

# LIVEWELL

dementia  
connections

SPRING/SUMMER 2022

\$10.00 CAD

.....

## Beyond Barriers

Breaking free from  
fear and stigma

.....

## Healthy Eating

How to address  
dietary challenges

.....

## Plus:

Tips for improving  
cognition, navigating  
the medical system,  
staying active  
and more

.....

# Changing Behaviours

The challenges of living with Frontotemporal Dementia

*Do you have a story to share?*

Are you a person with dementia or a care partner with a story to share about living well with dementia?

Is your team developing or providing innovative solutions to the challenges dementia can bring?

Our readers want to hear your stories and we will support you to share them. **Get in touch today!**



## WELCOME

### LIVE WELL

by *Dementia Connections*

#### EDITOR

Carolyn Brandly

#### PUBLISHED BY

Dementia Connections Canada Ltd.  
303-45 Bastion Square,  
Victoria BC V8W1J1  
dcpublisher@dementiaconnections.ca

#### EDITORIAL ASSISTANT

Jennifer Prescott

#### ART DIRECTION

Curious Agency

#### CONTRIBUTORS

Colleen Biondi, Elizabeth Chorney-Booth,  
Shannon Cleary, DICE Team, Lisa Kadane,  
Donna Paris, Sean Young.

Advertising inquiries  
collaborate@dementiaconnections.ca.  
Statements, opinions and viewpoints  
expressed within this publication do  
not necessarily represent the views  
of the publisher.

Copyright 2022 by Dementia Connections  
Canada Ltd. No part of this publication  
may be reproduced without the express  
written consent of the publisher.



#### EDITORIAL ADVISORY BOARD

Danielle Barrette-Marcuccio  
Lisa Despina  
Dr. Kate Dupuis  
Dr. Laura Booi  
Dr. Ron Posno  
Wayne Hykaway  
Stephanie Ruckstuhl

Did you notice?  
*Dementia Connections*  
magazine has been  
renamed *Live Well by*  
*Dementia Connections*.



This update to our name reflects the growing recognition globally that people with dementia have the right to live well, despite dementia, as do their care partners.

While there's still much to be done, it's encouraging to witness restrictive care paradigms of the past being dismantled, and the voices of people living with dementia guiding development of supports that enable a good life with dementia.

There is so much we can learn from people with dementia, and from care partners, about what it's like to live with dementia, how they make it work day-to-day, and about what they do to live well. Do you have a story to share about living well with dementia? We'd love to hear from you.

Thanks to our thoughtful Editorial Advisory Board members and hard-working Editorial and Design teams, we've got an exciting issue to share with you. In addition to our regular departments, our feature articles shine a light on frontotemporal dementia, explore how creative thinking can improve care, and investigate the individual and societal impacts of fearing dementia.

Dementia Connections has become more than a magazine. You'll find hundreds of new and past articles at [DementiaConnections.ca](http://DementiaConnections.ca), and while you are there, I hope you'll sign up for our newsletter to have inspiring stories, expert advice and the latest news and research about dementia delivered right to your inbox.

Wishing you a wonderful summer,

A handwritten signature in black ink, appearing to read "Carolyn Brandly".

**Carolyn Brandly, Editor**

Let's keep in touch! [editor@dementiaconnections.ca](mailto:editor@dementiaconnections.ca)

*dementia*  
connections



DementiaMag



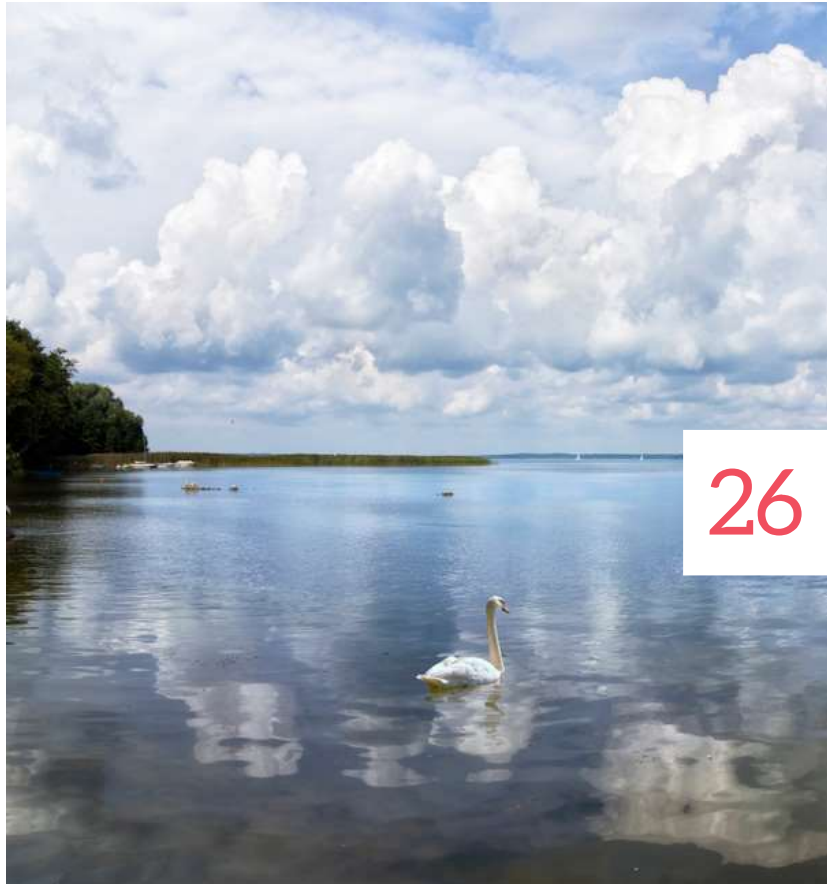
@dementia\_connections\_magazine



DementiaMag



dementia-connections



**IN FOCUS**

**The Moments Café** ..... 6  
Serving up comfort meals that spark conversation and memories.

**It's Time to Get Active** ..... 7  
Physical activity can improve the physical, mental and social well-being of people living with dementia and mild cognitive impairment.

**Early and Accurate Diagnosis** ..... 8  
Biomarker testing empowers people living with Alzheimer's disease.

**Word Swap** ..... 9  
Using person-centred language ensures the way we speak is respectful, life-affirming and inclusive.

**Lost and Found** ..... 10  
Biomarker testing empowers people living with Alzheimer's disease.

**PREVENTION**

**Improve Air Quality to Avoid Dementia** ..... 11  
The World Health Organization has added air pollution to the list of modifiable risk factors for dementia.

**FOOD AND NUTRITION**

**Eating Well at Home with Dementia** ..... 12  
Creative solutions to common dietary concerns for people living with dementia.

**ASK AN EXPERT**

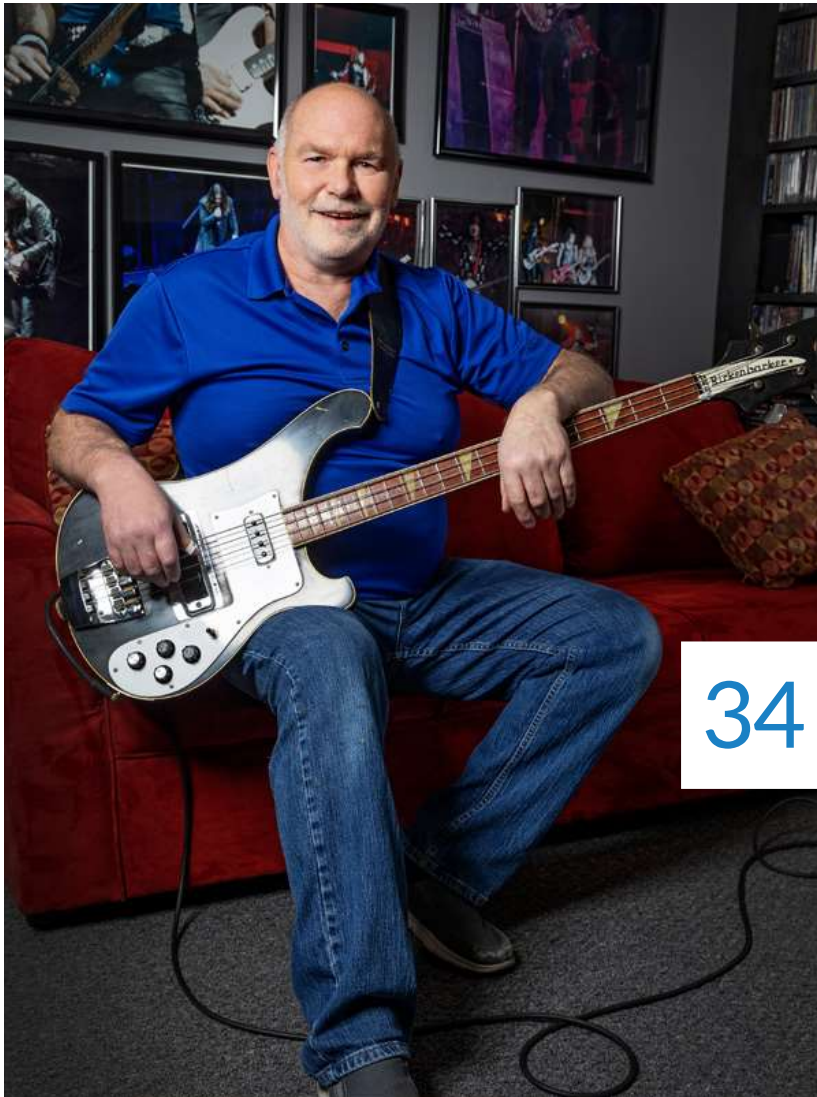
**Train Your Brain** ..... 14  
Dr. Nicole Anderson shares her insights into protecting and improving cognition.

**BREAKTHROUGH**

**Embracing Feedback** ..... 16  
Gamification and interdisciplinary teamwork make a difference in dementia care.

**CARE PARTNER WELLNESS**

**Navigating the System** ..... 20  
Tips for strengthening relationships between care partners and medical professionals.



**HOW WE MAKE IT WORK**

**Caregiving from Afar** ..... 23  
 Maintaining a long-distance caregiver relationship often comes with its own set of challenges and rewards.

**DESIGN FOR DEMENTIA**

**The Power of Soundscapes** ..... 26  
 Ambient sounds of birds chirping, ringing church bells or even keys tapping on a keyboard can help improve the well-being of people with dementia.

**AS TOLD TO**

**Shaping the Research Agenda** ..... 30  
 People living with dementia support researchers to identify issues and approaches for inclusion.

**LIVING WITH DEMENTIA**

**Patrick Ettenes** ..... 50  
 Navigating early-onset dementia through advocacy.

**ON THE COVER**  
 John McKenzie, photographed by Laura Joy Photography

**FEATURE STORIES**

**Shining a Light on Frontotemporal Dementia** ..... 34  
 This less-common brain disease affects personality and behaviour, and profoundly impacts lives.

**The County Day Program** ..... 42  
 Despite limited resources, a unique day program shows how teamwork, dedication and innovation can change long-term care.

**The Fear of Dementia** ..... 45  
 Breaking free from stigma by examining misconceptions and negative perceptions.



Vintage decor at Moments Café.

## The Moments Café

**Serving up comfort meals that spark conversation and memories.**

By Jennifer Prescott

**A woman sips from a piping hot cup of tea as she gazes at an analog clock resting on a weathered mantle.**

A retro 1950s television set – just like the one she had as a kid – complements the pastel pink wall paint. Though dementia has faded her memories, she smiles for a moment as homemade food and vintage decor return her to the good ol’ days.

This scene is what Moments Café in Plymouth, England, has strived to provide for its community members living

with dementia since it opened in March 2017.

Designed to spark conversation and memories, the café serves locally sourced comfort meals, from savoury roasts to delectable desserts, and offers decade-themed dining zones adorned with corresponding artifacts. Most notably, staff members take the time to get to know their visitors.

“We offer a warm, safe environment to eat, drink and socialize,” says Damian Chester, the café’s assistant manager. “Knowing we have a place where people can come to get help and dementia advice just feels so good.”

Chester, who lost both of his grandmothers to dementia, feels that his personal experience with the disease has deepened his connection to his work at the café, allowing him to take his hospitality to the next level. He says the rest of the staff is equally committed: “We learn customers’ names and we know when a lot of their birthdays are.

It’s those little things we try to always do.”

The cozy feeling the staff provides helps to create a place where the entire community wants to be. But Moments Café’s true novelty lies in its greater purpose, as it was built to sustain the Memory Matters hub, which is located above the café and offers free dementia support to those in need.

Co-founded in 2010 by nurses Kate Smith and Laura Walker, Memory Matters bases its work on Cognitive Stimulation Therapy (CST), which aims to increase brain engagement and social interaction while adding more meaning to peoples’ lives. Staff does this through hosting activities such as singalongs, arts and crafts sessions and various support groups.

“Everything we do is to help people with dementia thrive in our community,” says Shania James, dementia development officer for Memory Matters. “To see them smile really hits home for me that this is why I do what I do.”

Memory Matters also gives dementia resources and advice to people who come in for drop-in chats or by appointment.

But James and Chester agree that what is most important in their work is to provide that warm, community feeling in both the Memory Matters hub and the Moments Café.

“I love what I do, and I know how much of an impact it makes,” says Chester. “It just feels amazing to work at such a great place.” 🍵

# It's Time to Get Active

Exercise can improve the physical, mental and social well-being of people living with dementia and mild cognitive impairment. Experts recommend moderate to vigorous aerobic activity, strength training and balance exercises throughout the week, as well as light-intensity, regular movements every day.



Adapted from the Physical Activity Guidelines for People Living with Dementia developed by the Ontario Brain Institute and revised in partnership with the Dementia-Inclusive Choices for Exercise (DICE) Project.



|   |  |
|---|--|
|  <p><b>Strength Training</b></p>   | <p><b>HOW MUCH:</b><br/>2 days/week</p> <p><b>HOW INTENSE:</b><br/>Moderate to vigorous</p> <p><b>EXAMPLES:</b><br/>Squats or push ups, lifting weights, lifting heavy groceries</p>                 |
|  <p><b>Aerobic Activity</b></p>    | <p><b>HOW MUCH:</b><br/>30 minutes/day, most days of the week</p> <p><b>HOW INTENSE:</b><br/>Moderate to vigorous</p> <p><b>EXAMPLES:</b><br/>Brisk walking, swimming, aerobics classes, dancing</p> |
|  <p><b>Balance Exercise</b></p>  | <p><b>HOW MUCH:</b><br/>Daily</p> <p><b>HOW INTENSE:</b><br/>Light to moderate</p> <p><b>EXAMPLES:</b><br/>Tai Chi, standing on one foot, walking heel to toe in a line</p>                          |
|  <p><b>Everyday Movement</b></p> | <p><b>HOW MUCH:</b><br/>Every 2 hours</p> <p><b>HOW INTENSE:</b><br/>Light</p> <p><b>EXAMPLES:</b><br/>Use the stairs, move to music, gardening, walk to the store</p>                               |



Find dementia-specific resources for staying active at-home and in community at [DementiaExercise.com](http://DementiaExercise.com).

## Early and Accurate Diagnosis

**Biomarker testing empowers people living with Alzheimer's disease.**

By Carolyn Brandly

**People with concerns about their brain health can now access a biomarker test to get accurate answers sooner.**

"The Alzheimer's disease biomarker test can help doctors accurately diagnose the disease even when only mild symptoms are present," says Dr. Mari DeMarco, a clinical chemist at Providence Health Care and a clinical associate professor in the department of pathology and laboratory medicine at the University of British Columbia.

In July 2021, the Alzheimer's disease biomarker test became available to all Canadians through referral by a specialist, like a neurologist or geriatrician, who uses the results, in combination with other assessments, to determine whether someone might have Alzheimer's disease based on biomarkers that are found in the cerebral spinal fluid that surrounds the patient's brain.

"This is not a screening test for dementia," says DeMarco. "The test is not used to screen healthy people to see if they will one day develop dementia.

Instead, this testing is for someone who has signs and symptoms that a doctor deems are consistent with Alzheimer's disease and where the doctor believes testing would help arrive at a diagnosis."

DeMarco is also the principal investigator of the IMPACT-AD study, leading a team of researchers from across Canada to use the Alzheimer's disease biomarker test. Launched in 2020, the study first worked with participants from British Columbia to begin to develop a comprehensive understanding of how testing impacts medical and personal decision-making, and health care costs. The research teams are currently engaging participants Canada-wide, before the study concludes in late spring 2022.

"Through our IMPACT-AD study we are getting direct feedback from patients and also their care partners, and from them we are learning the value of early diagnosis in their journey," says DeMarco.


After undergoing Alzheimer's disease biomarker testing, study participants are invited to share their experiences and recommendations with researchers to improve the diagnostic process for future Canadians experiencing brain health concerns.

At an individual level, the conclusive results delivered by the Alzheimer's disease biomarker test can decrease anxiety about memory concerns and may empower people with Alzheimer's disease to plan for the future. Early and accurate

**"Through our IMPACT-AD study we are getting direct feedback from patients and also their care partners, and from them we are learning the value of early diagnosis in their journey."**

*- Dr. Mari DeMarco*

diagnosis can also promote open communication about brain health changes, and support those impacted to become advocates for themselves and others living with dementia.

More broadly, study results will be used to inform positive change in the health-care system to improve care and support for people living with Alzheimer's disease, and their families. 



Dr. Mari DeMarco



Learn more at [ImpactAD.org](https://ImpactAD.org)



# Word Swap

Using person-centred language ensures the way we speak is respectful, life-affirming and inclusive. Consider swapping outdated words for person-centred language.

## People

| INSTEAD OF                                 | CONSIDER                           |
|--|------------------------------------|
| Demented person, Dementia sufferer, Senile | <b>Person living with dementia</b> |
| Long-term care (LTC) home patient          | <b>Resident</b>                    |
| Informal caregiver                         | <b>Family care partner</b>         |

## Places

| INSTEAD OF   | CONSIDER                                    |
|--|---|
| LTC facility, Nursing Home, Old folk's home, Institution | <b>LTC home</b>                             |
| Adult day care   | <b>Adult day program or support program</b> |
| LTC unit   | <b>Neighbourhood or Home area</b>           |
| Admitted or placed, Discharged                           | <b>Moving in, Moving out</b>                |

## Actions

| INSTEAD OF                                   | CONSIDER   |
|--|--|
| Difficult behaviours, Challenging behaviours | <b>Responsive behaviours or personal expressions</b> |
| Violent behaviours                           | <b>Physical expressions of risk</b>                  |
| Triggers                                     | <b>Contributing factors</b>                          |
| Exit seeking or Wandering                    | <b>Exploring or Searching</b>                        |

## Items

| INSTEAD OF | CONSIDER                                   |
|------------|--|
| Diaper     | <b>Adult brief or Incontinence Product</b> |
| Bib        | <b>Clothing/shirt protector</b>            |
| Sippy cup  | <b>Glass, cup or mug</b>                   |

This content has been adapted from the Person-Centred Language (PCL) Word Swap poster, part of the PCL initiative and resources co-developed by Behavioural Supports Ontario (BSO) and the Ontario CLRI at the Schlegel-UW Research Institute for Aging with support from an expert panel. To learn more about PCL, visit [www.clri-ltc.ca/pcl](http://www.clri-ltc.ca/pcl).

# Lost and Found

Researchers are creating a dementia-approved GPS scale to ease the worry of wandering.

By Jennifer Prescott

**Getting lost can be a major concern for persons living with dementia and their care partners.** Traditionally, medications, restraints and physical barriers were used to ease this worry. But the recent consensus is to find ways to increase independence for people living with dementia while reducing care partner stress.

To this end, a rising number of people are turning to wearable locator devices, such as GPS-enabled watches, lanyards and shoe insoles. But with so many options available, there can be uncertainty in choosing a quality device.

Researchers at the University of Waterloo in Ontario are trying to help by developing a dementia-friendly universal scale to evaluate different devices, allowing future users to see how each rate.

“The scale’s purpose is to provide the information needed to make a right decision,” says Dr. Antonio Miguel-Cruz, lead researcher for the project. “If you get lost and you have a good device to locate you fast, it could be the difference between life and death.”

## Dementia-centred planning

Formally titled *Technology acceptance and usability of locator device scale*, its development began in 2020 with funding provided by AGE-WELL NCE, Canada’s technology and aging network. Rooted in theories of behavioural psychology, the scale is now in its final of three development phases:

### Phase 1: Assessing need

Researchers conducted a systematic literature review and confirmed that existing GPS scales were too complicated, confusing and inaccessible for persons living with dementia and their care partners, showing the need for such a scale.

### Phase 2: Designing

Five focus groups were held with care partners, people living with dementia, clinicians and technology developers to plan scale substance and design, with each group giving input on its needs and expectations.

Using this advice, researchers completed one version of the scale for care partners and a dementia-approved version, with special attention paid to font size, wording, colour and format. “It’s simple, fast, intuitive, comprehensive and based on co-design,” Miguel-Cruz says.

### Phase 3: Testing (current)

The scale will now be tested by 60 persons living with dementia and care partners to ensure it works and measures up against other scales in terms of information and usability.

**“If you get lost and you have a good device to locate you fast, it could be the difference between life and death.”**

– Dr. Antonio Miguel-Cruz

## Scale availability

After the scale is published academically in 2023, researchers intend to make it available to the public through a website, which will use the dementia-friendly design advice provided by the focus groups.

“People are eagerly waiting, not only people living with dementia and their caregivers, but also long-term care facilities, hospitals and community organizations,” says Miguel-Cruz. “We heard all the voices of the users – everything is based on what we know and on what they said – which is what makes the scale so important.”





# Improve Air Quality to Avoid Dementia

**The World Health Organization has added air pollution to the list of modifiable risk factors for dementia.**

**When considering potential risk factors for dementia, air quality may not be one that immediately comes to mind.** But that's changing. Researchers around the globe are investigating whether there is a link between air pollution and dementia, and they're finding some interesting connections.

For example, a 2021 multi-study review by researchers in the Middle East revealed that pollutants such as volatile organic compounds (VOCs) – hidden in the air at less than 2.5 parts per million and found both outdoors and indoors –

can cross the blood brain barrier and impact the central nervous system, resulting in cognitive decline and memory dysfunction.

Another study, conducted by the Keck School of Medicine at the University of Southern California, found that older women who were exposed to environments with the least amounts of two key air pollutants – fine particulate matter and nitrogen dioxide – were 14 to 16 percent less likely to develop dementia. Study results, released in January 2022, also noted a boost in cognitive function and memory for these subjects.

## How to avoid or reduce harmful pollutants in our air

When it comes to protecting ourselves from outdoor pollutants, it's important to limit our time spent in toxic air environments, heed the air quality recommendations reported on the weather channel and wear high-quality masks when air is particularly poor.

But what about protecting ourselves from the air pollutants that lurk indoors?

"We spend 90 percent of our time inside," says Susan Blanchet, founder and chief executive officer of Victoria-based Origen Air, a company that designs unique air purification systems for the home and office.

Blanchet, whose own father passed away from dementia in 2015, launched Origen Air partly as a way to help optimize both physical and cognitive

well-being. "Whatever we can do to collectively curb [dementia], we should be doing," says Blanchet. "One way is to pay attention to what we cannot see – to our air quality."

Here, Blanchet provides three of her favourite tips for improving indoor air quality:

**1 Consider hiring an air monitoring company to examine the quality of air in your home.** Although these companies may not be able to measure the finest toxic gases or particulates, they will give a broad-stroke assessment, which is a great start.

**2 Try your best to avoid any household practices that reduce air quality,** such as using cleaning products containing ammonia and chlorine, which are dangerous at high levels. Note that smoke from wood-burning fireplaces is also harmful, as it contains carbon monoxide.

**3 Check your cooling and heating systems regularly** so that the ventilation functions are working efficiently to maintain good air quality. Also, switch out your furnace filters regularly: "If you don't, it's like cleaning with a dirty rag," says Blanchet.

## 12 MODIFIABLE RISK FACTORS FOR DEMENTIA.

### Early life:

- Less-education

### Mid-life:

- Hearing loss

- Hypertension

- Obesity

- Excessive alcohol intake

- Head injury

### Later life (65+):

- Smoking

- Depression

- Social isolation

- Physical inactivity

- Diabetes

- Air pollution

Source: *The Lancet Commission 2020*

# Eating Well at Home with Dementia

## How to address dietary challenges.

**It's no secret that proper nutrition can play a significant, positive role in both our mental and physical well-being.** We are what we eat, so to speak, and a well-balanced diet, paired with sufficient hydration, can have tremendous benefits at any stage of a person's life.

But for many people living with dementia, establishing or maintaining healthy eating routines can be very challenging, which, in turn, can lead care partners to feel frustrated and concerned when healthy food and water intake becomes an issue.

## Common dietary concerns for people with dementia

While research has shown a potential link between nutrition

and dementia prevention, Dr. Heather Keller, a researcher at the University of Waterloo who specializes in nutrition in seniors, says there's not a lot of data on how specific nutrients can affect cognition in people who already have dementia. Nevertheless, since most people with dementia tend to be older, it's important for them – like it is for all aging adults – to adhere to a diet that incorporates plenty of protein, calcium and vitamin D to combat bone and muscle loss.

Of course, that can be easier said than done, especially if a person with dementia starts to lose interest in food, refuses to eat things they used to enjoy, or develops trouble chewing or swallowing – all of which are quite common. In those instances, maintaining not only important nutrients but also enough calories to keep weight on can become a problem.

Plus, dementia can make even the most beloved foods taste different, and people with dementia often develop “food jags,” which lead them to only want to eat certain things.

“One of the biggest concerns with people living with dementia is that they start to either change what they eat, or they just stop eating, and that leads to significant challenges with maintaining body weight,” Keller says. “Malnutrition in any person is not good. But a person with dementia will probably also have physical challenges happening because of their disease that impact food intake, leading to malnutrition.”

Keller says that hydration is also a common concern and, while some caregivers may be inclined to limit water intake in fear of worsening problems with incontinence, a lack of fluids can lead to issues with cognition and how medications are absorbed by the body. Since many people see a decrease in their thirst as they age, encouraging a person with dementia to drink enough water can also be a challenge.

## What can caregivers do?

In Keller's view, the main food goal for people with dementia and their caregivers should be to keep up that caloric intake and some sense of nutritional balance, while also accepting that mealtime will not necessarily look like it did before the dementia diagnosis.

One of the most important ways to encourage eating is for caregivers to sit down and eat with the person they're caring for. The act of eating together not only allows for quality time spent together, but watching someone else eat can also prompt the person with dementia to follow suit.

“Eating with others can have a huge impact, and research shows that mimicry – seeing someone else eat and drink – really is helpful,” Keller says. “When someone is eating with someone with dementia, it really does help them to eat as well, especially if they're facing each other rather than sitting side by side. The person with dementia can see the actions of someone else and mimic that.”



Dr. Heather Keller



**“Minimize the work of making food so you can spend the time eating with the person with dementia and enjoy the social connection.”**

*– Dr. Heather Keller*

It’s also essential to recognize that only eating at mealtimes might not be enough for some people with dementia, and that caregivers may have to adapt to their loved one’s changing needs. If a food jag means that the person with dementia only wants to eat peanut butter, for example, they can be presented with


different applications of that food (such as peanut butter on apples or celery instead of just crackers or toast).

Keller also recommends having easy-to-eat food at the ready for when the desire to eat may strike: a regular supply of healthy muffins on the kitchen countertop or sliced cheese in the fridge allows for more chances for spur-of-the-moment snacking. If the person with dementia gets anxious at the thought of sitting down at the table, liquid food like soup or smoothies can be served from a travel mug, with the extra bonus of some added hydration.

Ultimately, Keller doesn’t want caregivers to beat themselves up if mealtimes don’t look like they did before a dementia diagnosis. Meals don’t need to be complicated – things that are easy for the person with dementia to eat on their own and are bright in colour and high in flavour (for diminished taste buds) are good choices

that take the stress out of meal preparation and allow everyone to continue to enjoy the time they have together at home.

If a meal ends up consisting of cut-up vegetables with hummus and a few slices of cheese, caregivers can still consider that a win.

“A lot of it is about the pleasure of food, and about our food traditions. We need to recognize that healthy eating isn’t the only goal,” Keller says. “Keep trying to do different and small offers of food and fluid. You don’t have to spend a lot of time preparing food. Minimize the work of making food so you can spend the time eating with the person with dementia and enjoy the social connection.” 

# Train Your Brain

**Q+A: Dr. Nicole Anderson shares her insights into protecting and improving cognition.**



Dr. Nicole Anderson

**Research indicates that, no matter your age, there are actions you can take to improve your brain health.**

A new study out of Toronto's Baycrest Health Sciences centre is helping researchers better understand the aging brain. Titled "When I'm 64: Age-Related Variability in Over 40,000 Online Cognitive Test Takers," and led by Dr. Annalise LaPlume, the study examined data from 40,000 people who completed an online brain health assessment created by Baycrest subsidiary Cogniciti.

Focusing on the brain health of older adults and people living with dementia, the Cogniciti Brain Health Assessment measures spatial working memory, processing speed, facilitation, associative recognition and set-shifting through a series of tasks.

In analyzing assessment data, researchers found cognitive performance gradually declines over early and mid-adulthood, with faster and variable decline starting in the early 60s. Increasing differences in individual performance after 60 suggests causes besides age. With these results, researchers have identified risk factors and developed ways to protect and improve cognition.

Dr. Nicole Anderson, a senior scientist at Baycrest's Rotman Research Institute and co-author of the study, discusses these factors and offers tips on boosting brain health.

**Q: What makes us more likely to have cognitive decline?**

**A:** Risk factors include age, genetic makeup and how we live our life. It's about how cognitively engaged we are, what our exercise and eating habits are like, how socially connected we are and whether we address our sensory deficits such as hearing and vision loss.

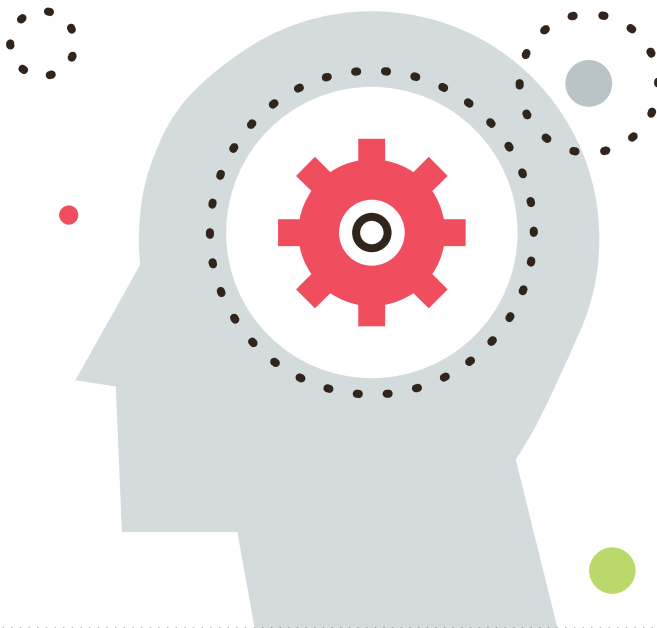
For example, bilingual people develop mild cognitive impairment and dementia about four years later than monolingual people do, and people with higher levels of education are less likely to develop dementia and do so later.

**Q: How can we keep our brain healthy?**

**A:** We should:

- Exercise with moderate to vigorous intensity for two and a half hours a week.

**“Stay physically active, try to eat well, try to stay calm and cognitively and socially engaged. That is going to help slow down cognitive decline.”**  
– Dr. Nicole Anderson



- Eat a healthy diet, such as the Mediterranean-style diet, where proteins come from fish and lean white meats.
- Eat fruits, vegetables and whole grains.
- Stay cognitively active.
- Stay socially connected.
- Use a hearing aid, if needed.
- Avoid head injuries.

**Q: How can people living with cognitive decline improve their brain health?**

**A:** The most effective thing is a lifetime of living healthy, but it's never too late. Even older adults who start learning a new language have increases in cognitive functioning.

Again, try to stay physically active, try to eat well, try to stay calm and cognitively and socially engaged. That is going to help slow down cognitive decline.

**Q: Why is it important to address diagnosed cognitive changes early?**


**A:** Addressing all these risk factors, such as cognitive engagement, social connectedness and sensory deficits, helps build cognitive reserve so that you have better brain health to live longer, even if you're having Alzheimer's pathology building up in your brain. If you can raise levels of cognitive functioning earlier, you'll enjoy more years in cognitive health.

**Q: What cognitive improvement tools does Baycrest offer?**

**A:** Take the free, 20-minute Cogniciti Brain Health Assessment online. It will tell you whether you should go see your doctor. I encourage using Cogniciti even just to see where you're at.

There's the Cogniciti Smart Tracker, which looks at risk

factors, eating habits, physical activity, mental health and things like that. And it gives advice about how to address those factors.

Baycrest also has a food guide, a very active memory clinic and top-notch neurologists and psychiatrists working at the Koschitzky Centre for caregivers. 



For more information on the resources available through Baycrest, visit [baycrest.org](http://baycrest.org).

# Embracing Feedback

Two initiatives helping to make a difference in dementia care.

By Elizabeth Chorney-Booth



## Sea Hero Quest Mobile Research Game

**One of the challenges that many academic researchers face is finding a large enough sample of participants to build a comprehensive data set.**

Convincing the public to engage in research projects isn't always easy, especially when experiments are invasive or time-consuming. A group of scientists in the UK has found a new way to encourage people to participate in an academic experiment in order to collect invaluable data to help with early dementia diagnoses. They're doing it through a wildly popular video game called Sea Hero Quest.

Sea Hero Quest was developed by a multidisciplinary team at the University of East Anglia in Norwich and University College London in 2016 as a way to measure players' spatial navigation. On the surface, Sea Hero Quest looks like a recreational video game where players take on the role of a son attempting to recover his father's lost memories by adventuring through an ocean environment. It's designed to be fun, while also measuring navigation and orientation skills.

For the first phase of their research, the team behind Sea Hero Quest released the game to the general public through traditional app platforms so that they could collect information from people who were not necessarily at a higher-than-normal risk of developing dementia.

The researchers were hoping to capture data from 100,000 participants but ended up attracting more than four million players from around the world over the course of six months, making it the world's largest study of spatial navigation. Players were told upfront that they were participating in a research project and were also provided with some educational information about dementia and Alzheimer's disease.

"We wanted to reach as many people as possible," says the University of





Left: Image from Sea Hero Quest

Right: Dr. Michael Hornberger

East Anglia's Michael Hornberger, who developed the original idea for the game. "We realized very quickly that having people do a scientific task can be boring for them, so we came up with the idea of doing a game. Gaming has a lot of spatial navigation and the ability to move through different levels. That was the premise for starting Sea Hero Quest and it really went beyond our expectations."

Sea Hero Quest came about as a unique collaboration between dementia and cognition researchers as well as tech and gaming experts. The team from the University of East Anglia in Norwich and University College London worked with web developers BoldLight and the Glitchers game developers to come up with a game that would be both appealing and scientifically valuable. In all, the game came together in a short nine months.

After collecting that initial data from the general public, Hornberger and his colleagues removed the game from the app platforms to put together the data set.

In 2018, the game re-emerged as a tool specifically for researchers to study healthy players and those at risk of Alzheimer's disease and is now hosted by Alzheimer's Research UK. With such a large data set from the game's consumer run, researchers can compare the performance of their at-risk participants with players from the general population of the same age, gender and geographical location.

Spatial navigation is often affected by Alzheimer's disease before memory loss can be detected, so having a better way to detect subtle deterioration through a tool like Sea Hero Quest could be a game-changer in early diagnoses. While Hornberger acknowledges that there is no cure for Alzheimer's, diagnosing the disease in its earliest stages can mean



that the progression can be potentially slowed through emerging interventions.

"People often ask why they would want to know if they have Alzheimer's this early because there's no treatment for it. That's a valid point," he says. "But we know now that some lifestyle changes can reduce the risk of dementia, and that's a key aspect of this research."

**"We know now that some lifestyle changes can reduce the risk of dementia, and that's a key aspect of this research."**

*- Dr. Michael Hornberger*

Hornberger says that he doesn't expect to see patients playing Sea Hero Quest on their phones in their doctors' offices, but he does believe that the studies using Sea Hero Quest will result in

diagnostic tools for early dementia detection.

He's also pleased that his work has proven that thinking outside of the confines of traditional scientific research has resulted in something that can help his fellow researchers for years to come.

"It's very unusual for researchers to do a game like this," Hornberger says. "Lots of researchers gamify their research, but very few people have developed a proper game like we did. For a long time, many people in the research community said that what we were doing was just a game and not proper science. But once we started publishing our data, people realized it can generate valid information. Now, with more and more findings, people are getting very excited about it." 🗨️



## PSW Perspectives on Quality Care

**Everyone working within the dementia care community has a common goal of providing the best quality of care possible to people living with dementia.** How that

care is provided may differ from organization to organization. And, while nurses, doctors and academics often share a variety of perspectives on what constitutes the best care possible in various articles and studies, one group of stakeholders that often gets less say when it comes to their point of view are personal support workers (PSWs).

PSWs work directly with people with dementia and are usually the front line of care in both private homes and long-term care facilities. In most cases, PSWs have less training and credentials than other members of a care team, which means their opinions are often regarded with less gravity than that of a doctor or nurse, even though they tend to spend more one-on-one time with people with dementia than any other professional caregivers.

This is why Dr. Marie Savundranayagam and her colleagues at Western University's CARE Lab and the Sam Katz Community Health and Aging Research Unit wanted to study the perspectives of PSWs when it comes to providing high-quality care to clients with dementia.

In December 2021, Savundranayagam and her team published a paper titled "Quality home care for persons living with dementia: Personal support workers' perspectives in Ontario, Canada," in the journal *Health and Social Care in the Community*. The paper reported on the experiences of 15 Ontario-based PSWs who were interviewed by the research group over a few months in late 2019 and early 2020.

"We asked the open-ended question, 'What does quality of care for persons living with dementia look like to you?' We really wanted to understand their perception of quality of care," Savundranayagam says.

"Through that interview process we identified several themes that emerged related to what quality of care means to people on the front line."

Many of the themes that Savundranayagam uncovered echo the documented concerns of other dementia care workers. Specifically,

the PSWs pointed to the importance of individually tailored, person-centred care, a common call in the current thinking about dementia care.

The day-to-day aspect of the PSW role puts the participants in intimate proximity to the people that they're caring for, and that closeness led to some more specific comments as well. The study found that PSWs believe that a consistency of care and the pairing of clients with the same PSWs on a regular basis are both important for high-quality care. They also recommend that family care partners be given more formal support in navigating the care system.

Those interviewed also offered some insight on aspects that could help them to better perform their jobs and contribute

**"Our paper really is about including the people who are doing the most work and are providing the most care but get the least support." – Dr. Marie Savundranayagam**



Dr. Marie Savundranayagam

to that overall picture of person-centred care. Savundranayagam says that many of the participants stated that, in general, PSWs aren't provided with proper training or access to new cutting-edge information in the same way that a doctor or registered nurse would be. They also often don't feel respected as part of a client's larger support team. In some cases,

some of the participants said they aren't even briefed on a client's full history or other information that could be essential in providing the very best care.

"PSW really want to be included as part of the interprofessional care team," Savundranayagam says. "They're working with family care partners, nurses and doctors and they want to be included so that everybody's on the same page. PSWs spend the most time with their clients living with dementia and need to be actively involved in those interprofessional care teams."

As one PSW who participated in the study put it: "The LHIN [Local Health Integration Network] come in, they do their assessment, they leave. They don't see the changes. They're not with the person every day or every week. The only person that's going to see that is the family members and the PSW. So, ideally, the care plan should involve everybody."


Finally, the respondents asked for a call to action for agencies to better respect and support PSWs so that they have the

time and ability to treat clients with an equal degree of dignity and respect. In this regard, PSWs who work independently rather than with an agency said that being able to facilitate their own schedule instead of rushing from assignment to assignment allows them to give each client the attention they deserve.

**"PSWs spend the most time with their clients living with dementia and need to be actively involved in interprofessional care teams." – Dr. Marie Savundranayagam**

Savundranayagam says she hopes that other health-care workers take the PSWs' concerns to heart and work to make them feel included and heard. With everyone having the same goal – providing excellent treatment for those with dementia – it makes sense

to put real value in the voices of those interacting directly with those with dementia.

"Advocating to be part of an interprofessional team is a fair ask because PSWs have frequent contact with clients with dementia and therefore are the ones who can see the changes that the person with dementia may be experiencing," Savundranayagam says. "Our paper really is about including the people who are doing the most work and are providing the most care but get the least support. Part of our research is to advocate for PSWs because, apart from family care providers, they are the backbone of the formal care system." 

# 15

## Ontario-based personal support workers

were interviewed by the research group.

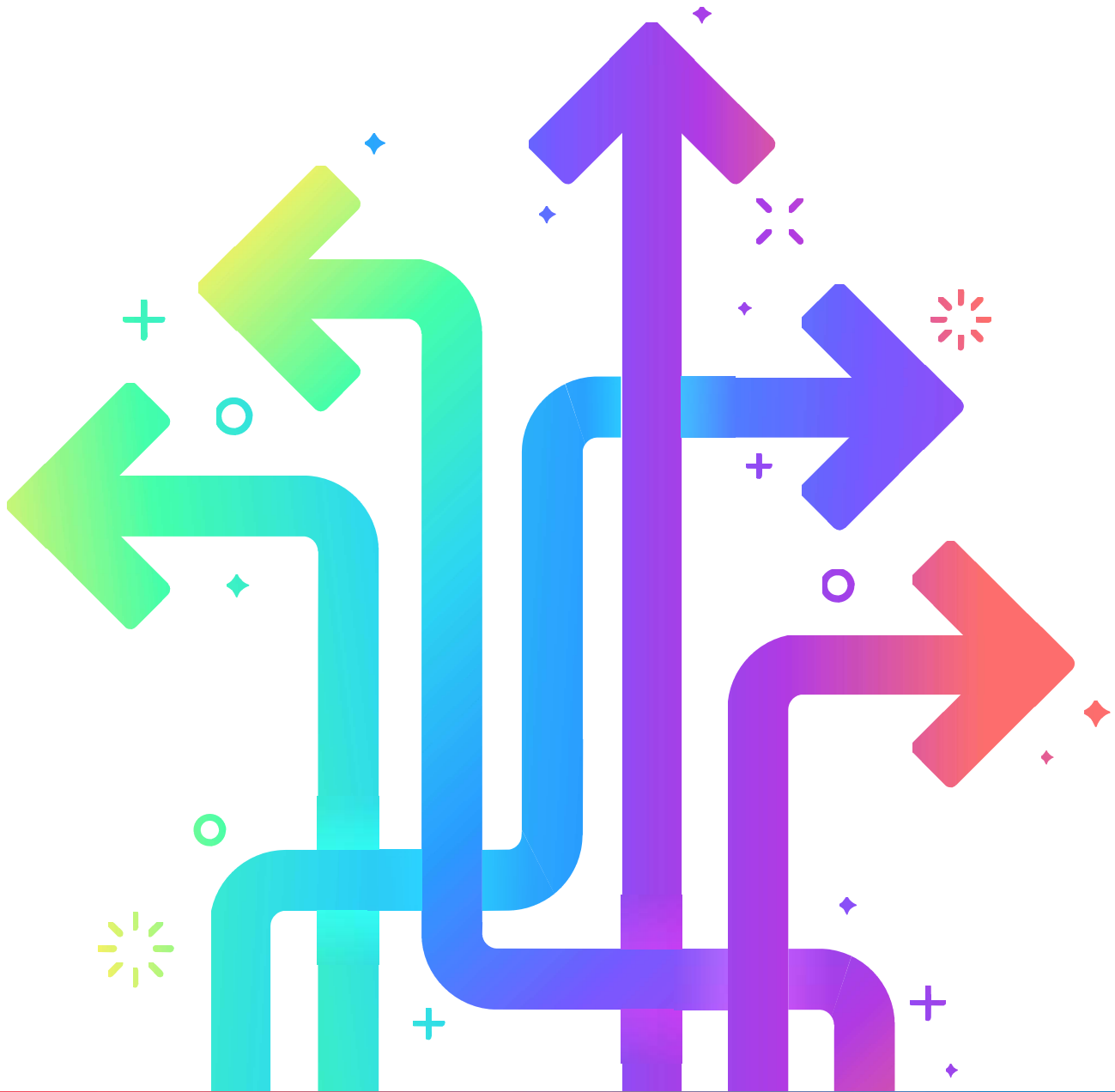
### Several themes emerged

related to what quality of care means to people on the front line:

PSWs have unique knowledge to contribute to interdisciplinary teams.

PSWs believe consistent pairing with clients enables them to receive higher quality care.

Access to ongoing professional development will help PSWs to contribute to person-centred care.



By Sean P. Young

## Navigating the System

**Tips for strengthening relationships between care partners and medical professionals.**

**Care partners and their loved ones living with dementia set out on a journey together from the moment of diagnosis.**

Throughout that journey, they interact with a variety of medical professionals who will work with them to provide direction, assistance or treatment.

As with any journey, it's important to recognize, anticipate and address any challenges and stressors that may come up along the way. Here, two care experts identify some of the key obstacles that tend to arise while seeking and receiving medical care for people with dementia. They also share some simple tips for dealing with those obstacles effectively.



**“I often tell the caregivers I support to keep a journal of things that you’re observing with the person you support.”**  
– *Samantha Norberg*

## **THE OBSTACLE:** Time

## **THE WORKAROUND:** Staying organized

Often, a diagnosis of dementia seems to blur or constrain time for the individual and their care partner. It takes time to figure things out; time to research and schedule appointments.

And yet, the pace at which things move once you’re in the medical system can make it feel like there’s not nearly enough time to make important decisions.

“The system doesn’t adequately reward or remunerate primary care practitioners (PCPs) for spending time with people who are living with dementia and their care partners,” says Dr. Elisabeth Drance.

Now semi-retired, Drance currently works for Providence Health Care in its Dementia Caregiver Resilience Clinic and is a clinical associate professor of psychiatry at the University of British Columbia. She is also a certified mindfulness

medication teacher and works in private practice as a dementia-care coach.

Drance advises care partners and doctors to work together to help to alleviate that time-crunch feeling by communicating via email before appointments. Many medical professionals welcome a short email from care partners – in which they summarize their key concerns – because it can help everyone get the most out of appointments and feel less rushed. Additionally, it allows PCPs to zero in on what is most important to discuss.

Care partners can also help maximize everyone’s time by getting organized before appointments and interactions with medical professionals.

“I often tell the caregivers I support to keep a journal of things that you’re observing with the person you support,”

says social worker Samantha Norberg, who works with Jewish Family Services Calgary (JFSC).

Norberg provides individual counselling for care partners of seniors and runs the Caregiver Support and Memory Care group programs at JFSC. She says that, in addition to organizing observations and questions via a journal, casting the role of communicator – one individual within a family who can become the consistent representative for the person living with dementia – can be beneficial.

“You’re more likely to have those professionals get to know you, to remember your name,” Norberg says. “And that relationship-building is so important. The more consistent we can keep it, the better outcomes we’ll see for that family.”

*“When you take on the care of somebody with dementia, you’re actually going to be treating a family.” – Samantha Norberg*

## **THE OBSTACLE:** Knowledge gaps

### **THE WORKAROUND:** Finding the right resources

According to Drance, care partners often have a very limited understanding of dementia, especially if their loved one has been recently diagnosed. It can be hard to communicate with someone who is an expert in the disease if they’re not willing to come down to your level of understanding.

“It’s incumbent on health-care professionals to seriously consider ways that information can be shared in plain language,” Drance says.

She adds that medical professionals need to be patient

and bring the care partner and their loved one back for more conversations. Care partners can help close the knowledge gap by seeking out information from accredited sources, Drance says.

“Don’t think you can find it all on Google; get it from the places that can give you the real goods,” she says.

One good place to start is the Alzheimer’s Society of Canada ([alzheimer.ca](http://alzheimer.ca)); there, you can find answers to lots of key questions, along with further resources that will be

tailored to you and your loved one’s specific needs.

Determining who to contact is another source of confusion for many care partners, especially as more medical professionals are added to the care team.

“There are always questions, especially when there’s specialists involved, of who does what, and who will have time for me,” says Norberg. “And that can be a significant stressor. How I approach that with families is usually by telling them to go to their family physician first, as kind of a home base.”

## **THE OBSTACLE:** Hesitancy

### **THE WORKAROUND:** Identifying and voicing concerns

Like with any relationship, it can be hard to find the right tempo between people living with dementia, their care partners, and medical professionals.

Drance says generational differences can also make it difficult for everyone to get on the same wavelength.

“Our older seniors typically respect the authority of health care professionals, and often they won’t voice concerns if they’re not asked,” she says.


To mitigate this, Drance suggests that, when possible, medical professionals carve out five minutes at the end of

visits to talk to care partners separately. She says this can be done tactfully as a mere courtesy and often reveals important things that can improve care.

“This is a key component of dementia care – when you take on the care of somebody with dementia, you’re actually going to be treating a family,” she says.

Norberg adds that care partners need to recognize their own stresses and not feel hesitant about seeking out assistance whenever they can. The care partners she works with often find solace

in receiving respite, getting grief counselling, or by joining support groups.

“It’s really important to look at what’s most stressful about caregiving at [any moment along the dementia journey]. That will help you access the right support,” she says. 

# Caregiving from Afar

Maintaining a long-distance caregiver relationship often comes with its own set of challenges – and rewards.

**When Karla Wilson's mother, Karen, started showing symptoms of dementia in 2010, Wilson knew that she wanted to be involved in her care.** But with Karen and her other two adult children living in Toronto and Wilson on the other side of the country in Victoria, B.C., taking on a traditional family caregiver role just wasn't possible.

Now, over a decade since their mom started showing signs of decline, Wilson and her siblings have worked out a system where they are all involved in her care, whether it's from the same house or 4,000 kilometres away.

Recently, Karen moved from the home where she raised her family to live with her eldest daughter in Toronto. Wilson does everything she can to provide support remotely from Victoria. Here, in her own

words, Wilson shares how she maintains a long-distance caregiver relationship with her beloved mom:

## A different kind of care

"Over the years, with me living in British Columbia, I've obviously been very far away from the situation. The bad part about that is that I haven't been able to be a care provider to Mom on a day-to-day basis and I can't physically be there for her. But the positive part is that I'm able to go and see things more objectively in terms of my mom's disease progression and in terms of decline in cognition, her ability to be safe, and her energy and health.

"Also, I've been able to connect with her via telephone. We weren't able to get in early enough to teach her how to use an iPad and do video calling,

**"The positive part is that I'm able to go and see things more objectively in terms of my mom's disease progression and in terms of decline in cognition, her ability to be safe, and her energy and health."**

*– Karla Wilson*

but I phone about three times a week now and send letters or cards whenever I'm able. I've also created photo books of the family, which she really enjoys."

## Finding creative solutions

"In 2019 and 2020 my family went out not only to see Mom in Toronto, but to take her out of the home and spend time in a different part of Ontario.

Karla Wilson

We rented a cabin with my siblings and their families, trying to create memories and moments where my mom feels connected and loved and like she's with all of her favourite people in the world. My sister and I try to think creatively about the things that I can provide as a long-distance caregiver, which never feels like enough because I'm not there.

"I'm not going to say I feel guilt, because that's a terrible emotion, but I have a strong desire to assist with the situation. I want to make sure my mom is in the best possible situation and that my sister also feels supported and cared for."

### **Closing the geographic gap**

"I spend a lot of time in advance preparing for my trips, which I try to take to Ontario every six months or so, because there's always a job to do. It's not just sitting and visiting my mom – there's always something to do to support and help.

"My role now is to start looking for long-term care and figure out what will be the best care homes to visit when I go on my next trip. I also want to focus on how I can help my sister by taking some of the burden of being a full-time family caregiver off of her. From afar, I can offer my time in that way. Through technology I can set up appointments, do some research on whatever needs to be done next, and prep myself far in advance.

"It's amazing how much activity can be crammed into

the space of a week or 10 days. I'm sure I can be perceived as a bit of a hurricane when I come in because I bring in so much change."

### **Spending time intentionally**

"On my future trips I'll be asking my sister when she needs some relief. My life and my travel plans revolve around what my mom needs and how to support my sister best. I work in communications for Family Caregivers of B.C. and made a very conscious choice to apply for this position in 2021. It's the ideal organizational fit for this time in my life because of the support it offers in terms of balancing work and care.

"When I'm in Ontario I can work full-time from my sister's home. The benefits of a caregiver-friendly workplace have allowed me to plan my year ahead as a long-distance caregiver. I wish all organizations could be as supportive to family caregivers in the workplace. I give my all to my organization because I recognize and appreciate the support and flexibility they offer me, and I clearly believe in their mission to improve the quality of life of family and friend caregivers."

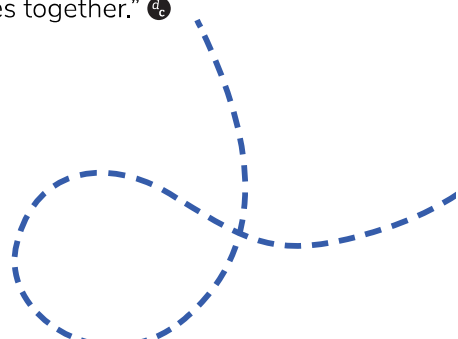
### **Everyone plays their part**

"There's value in all of the roles that my siblings and I play. My brother offers a tremendous amount of companionship, love and activities to keep my mom stimulated and connected with her family. My sister is the

**"There's value in all of the roles that my siblings and I play... It's interesting how we can all collaborate and use our different skill sets and roles to make things work for Mom."**

*– Karla Wilson*

boots-on-the-ground person, making sure things get done. And I'm the big picture change-maker. I get to see things from a different perspective. It's interesting how we can all collaborate and use our different skill sets and roles to make things work for Mom.

"My dad passed away from cancer when I was 23 and I really see the value of spending time with the people I love and how short life really is. I know that I will never regret spending money or vacation time to be with my mother while we still have her. I know that the disease is progressive, but she still recognizes all of us. She still feels love and joy and we have a lot of great laughs and fun times together." 



## WILSON'S TIPS FOR LONG-DISTANCE CAREGIVING



### Use technology.

Set up a regular video call (if your loved one is able) or ask friends or relatives who are with your loved one to call you when they are together.



### Create memories when you visit.

Take your loved one on a special excursion or out to a favourite restaurant. Take as many photos as possible.



### Make a photo book, album, or calendar

of memories of your time together. Alternatively, print photos and send them in regular intervals to remind your loved one that you're thinking of them.



### Write and send emails or letters,

letting your loved one know what's happening in your life. Even just telling them what you've been doing during the week can help them feel connected.



### Keep note of your loved one's important appointments or events.

Follow up with them afterwards for updates. Even if remembering the details is difficult for your loved one, it's kind to show you remembered details of their day.



### When you're able to see your loved one in-person, try your best to be present on their schedule.

Spend quality time together, rather than making your visit a whirlwind of activity.



### Send or bring a gift from your hometown

– something as simple as a fridge magnet can remind your loved one of you.



### Engage your own family in long-distance caregiving.

If you have children, ask them to write letters or create some artwork, depending on their ages.



## REGAIN YOUR BALANCE

Inspiring stories, expert advice and the latest research news to support you to live well with dementia.

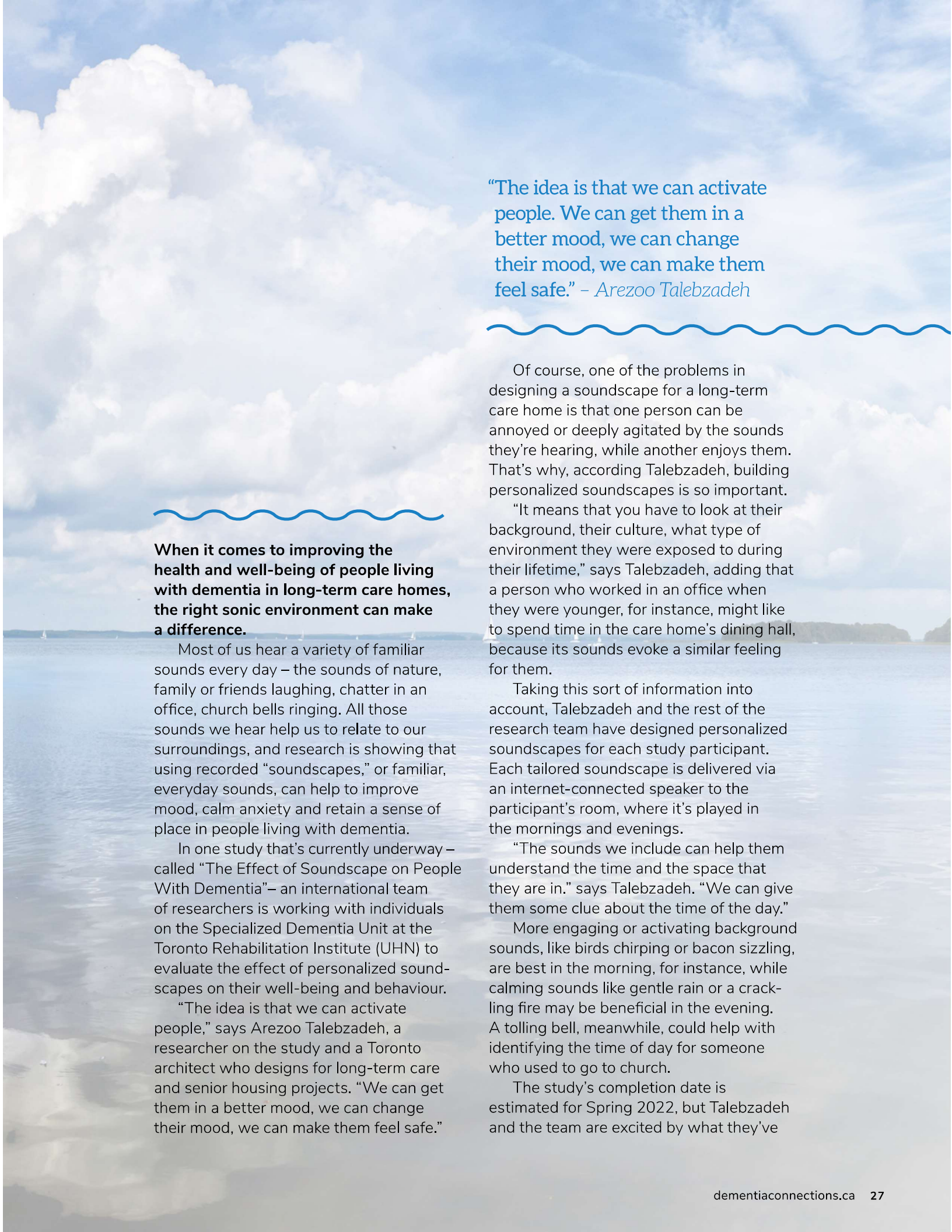
Sign up today to have our free Connections Newsletter delivered right to your inbox.




# The Power of Soundscapes



Ambient sounds of birds chirping, ringing church bells or even keys tapping on a keyboard can help improve the well-being of people with dementia.



**“The idea is that we can activate people. We can get them in a better mood, we can change their mood, we can make them feel safe.” – Arezoo Talebzadeh**



**When it comes to improving the health and well-being of people living with dementia in long-term care homes, the right sonic environment can make a difference.**

Most of us hear a variety of familiar sounds every day – the sounds of nature, family or friends laughing, chatter in an office, church bells ringing. All those sounds we hear help us to relate to our surroundings, and research is showing that using recorded “soundscapes,” or familiar, everyday sounds, can help to improve mood, calm anxiety and retain a sense of place in people living with dementia.

In one study that’s currently underway – called “The Effect of Soundscape on People With Dementia” – an international team of researchers is working with individuals on the Specialized Dementia Unit at the Toronto Rehabilitation Institute (UHN) to evaluate the effect of personalized soundscapes on their well-being and behaviour.

“The idea is that we can activate people,” says Arezoo Talebzadeh, a researcher on the study and a Toronto architect who designs for long-term care and senior housing projects. “We can get them in a better mood, we can change their mood, we can make them feel safe.”

Of course, one of the problems in designing a soundscape for a long-term care home is that one person can be annoyed or deeply agitated by the sounds they’re hearing, while another enjoys them. That’s why, according to Talebzadeh, building personalized soundscapes is so important.

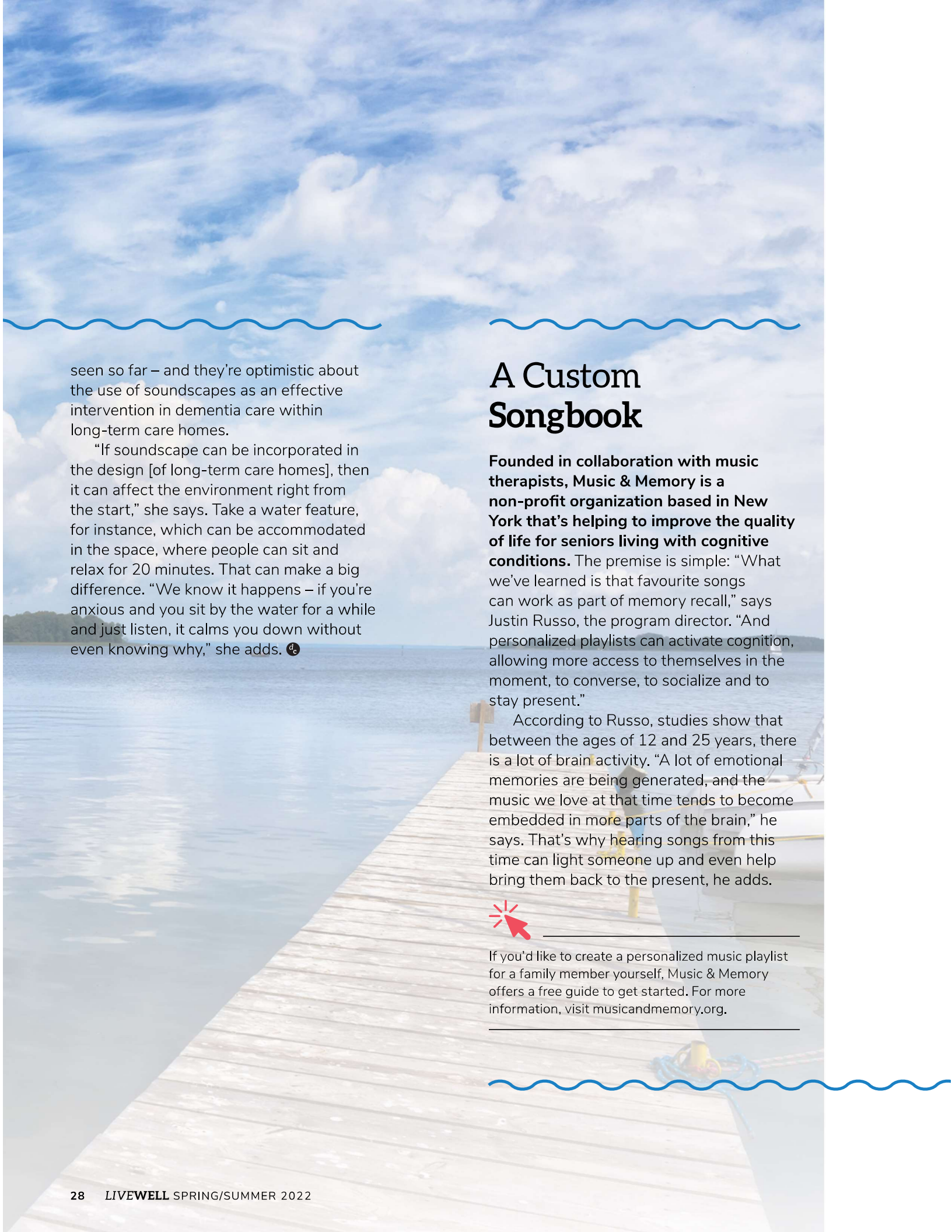
“It means that you have to look at their background, their culture, what type of environment they were exposed to during their lifetime,” says Talebzadeh, adding that a person who worked in an office when they were younger, for instance, might like to spend time in the care home’s dining hall, because its sounds evoke a similar feeling for them.

Taking this sort of information into account, Talebzadeh and the rest of the research team have designed personalized soundscapes for each study participant. Each tailored soundscape is delivered via an internet-connected speaker to the participant’s room, where it’s played in the mornings and evenings.

“The sounds we include can help them understand the time and the space that they are in,” says Talebzadeh. “We can give them some clue about the time of the day.”

More engaging or activating background sounds, like birds chirping or bacon sizzling, are best in the morning, for instance, while calming sounds like gentle rain or a crackling fire may be beneficial in the evening. A tolling bell, meanwhile, could help with identifying the time of day for someone who used to go to church.

The study’s completion date is estimated for Spring 2022, but Talebzadeh and the team are excited by what they’ve



seen so far – and they’re optimistic about the use of soundscapes as an effective intervention in dementia care within long-term care homes.

“If soundscape can be incorporated in the design [of long-term care homes], then it can affect the environment right from the start,” she says. Take a water feature, for instance, which can be accommodated in the space, where people can sit and relax for 20 minutes. That can make a big difference. “We know it happens – if you’re anxious and you sit by the water for a while and just listen, it calms you down without even knowing why,” she adds. 🎧

## A Custom Songbook

**Founded in collaboration with music therapists, Music & Memory is a non-profit organization based in New York that’s helping to improve the quality of life for seniors living with cognitive conditions.**

The premise is simple: “What we’ve learned is that favourite songs can work as part of memory recall,” says Justin Russo, the program director. “And personalized playlists can activate cognition, allowing more access to themselves in the moment, to converse, to socialize and to stay present.”

According to Russo, studies show that between the ages of 12 and 25 years, there is a lot of brain activity. “A lot of emotional memories are being generated, and the music we love at that time tends to become embedded in more parts of the brain,” he says. That’s why hearing songs from this time can light someone up and even help bring them back to the present, he adds.



---

If you’d like to create a personalized music playlist for a family member yourself, Music & Memory offers a free guide to get started. For more information, visit [musicandmemory.org](https://musicandmemory.org).

---

Niels Eje



“The calming repertoire contains sounds from nature, which helps to create and revive memories of experiences of nature that the person has experienced earlier in life.”

– Niels Eje

## Tuning in to MusiCure

**It’s no secret that certain types of music can help to alleviate stress and calm nerves.** This notion is what drove Denmark-based composer and musician Niels Eje to create MusiCure, a collection of specially composed, instrumental soundscapes created specifically for the health-care sector.

The journey to founding MusiCure began in the 1980s – that’s when Eje first began working with both classical and “crossover” repertoires, creating instrumental compositions that were pleasing to the ear, and soothing to the mind.

“Imagine tunes by Lennon/McCartney, Paul Simon, Brian Wilson and jazz composers like Chick Corea and Quincy Jones in arrangements for [classical] instruments, as well as many of my own compositions,” Eje describes.

The recordings reportedly appealed to many listeners


and helped them with stress relief. Then, in the late 1990s, a doctor at Copenhagen University Hospital urged Eje to create his own original music so that it could be played for patients at the hospital. Eje obliged, creating compositions that consisted of instrumental soundscapes, performed on acoustic instruments by classical soloists, as well as recordings of nature sounds, which were carefully selected and integrated into the music.

At the hospital, speakers were installed in the ICU, and researchers conducted studies on the effect of Eje’s music on patients. The results were so positive that the idea of using specially composed music quickly spread to the other university hospitals in the country, and subsequently to other Scandinavian countries.

“The calming repertoire contains sounds from nature, which helps to create and revive memories of experiences with nature that the person has experienced earlier in life,” says Eje, adding that the purpose of the music is provide a “positive

distraction” that sends the listener on a relaxing sound journey. And that, he says, is what really resonates for people with dementia: reassuring and universal musical elements that create deep peace and rest.

The MusicCure program is now being used in hospitals (including UHN and North York General Hospital in Toronto), clinics and care centres, as well as by therapists and private users.

Recently, Eje and his wife, Inge (also a trained classical musician and producer), also launched their own streaming service, offering their music, films and special treatment programs to institutions, hospitals and individuals worldwide. 



---

For more information, visit [musicurestream.com](http://musicurestream.com).

---

# Shaping the Research Agenda

**An important new program is enabling people with lived experience of dementia to advise on dementia-related research.**

In early 2020, the Canadian Consortium on Neurodegeneration in Aging (CCNA) launched a new program to bring voices of lived experience into the CCNA research process. The program, called Engagement of People with Lived Experience of Dementia (EPLD), enables persons with dementia and their care partners to provide meaningful insight and counsel to CCNA research teams. Up until relatively recently, researchers around the world have largely ignored the perspectives of people with dementia, failing to take into account that their insights, abilities and diverse perspectives can lead to more effective studies and outcomes.

The EPLED advisory group consists of 16 people of different backgrounds and geographical locations in Canada – some of whom are living with dementia, and others who are (or have been) care partners to loved ones living with dementia.

Since their very first meeting in July 2020, members of the EPLED team have advised on a number of research projects, contributed to academic papers, served on dementia discussion panels and more.

Recently, *Dementia Connections* had the honour of speaking to 12 of the 16 EPLED members about the work they're doing as advisors and what it means to them. Here's just some of what they had to say:



"For me, the most rewarding part of EPLED is the actual meetings – looking at people in similar situations to me and talking to researchers who are interested in my problems and in what I've experienced. As EPLED members, I liken what we do to a coaching role. We just try to give the researchers a little guidance to make their work a little better."

—JODY PETERS, CARE PARTNER



"The EPLED committee has been able to have really great conversations around medication, long-term care, decision-making. Those aren't easy conversations, but they've been really honest ones, and people have been really forthcoming. Everyone has a totally different perspective, which I think is the result of the care with how people were selected for the group. And I think we're seeing the value of that care play out in the diversity of the conversation."

—CATHERINE ANN KELLY, CARE PARTNER

## EPLED MILESTONES

### JUNE 2021

Co-authorship of COVID-19 and Dementia Taskforce publication entitled "Social Connection is Essential in Long-Term Care Homes: Considerations During COVID-19 and Beyond."

### JULY 2021

Involvement in lay summary preparation for a statement on dementia drug aducanumab: "Consensus statement regarding the application of Biogen to Health Canada for approval of aducanumab."



"I've been living with vascular dementia for 10 years, and I've been part of many different groups and research projects. The thing I like about this one is that when everybody is talking, it's in language I can understand. I'm not an academic, and I think everybody knows I hate acronyms. I truly appreciate the inclusivity that this group offers. It makes me feel comfortable." –PAUL LEA, PERSON LIVING WITH DEMENTIA



"When you don't know what you don't know, it's hard to ask questions. But through involvement with groups like EPLED, where we connect with other projects and teams, we can learn what questions we have to ask. We get a lot of knowledge just by listening to other people talk. To get the perspective of someone who has dementia, it's a phenomenal learning environment. It gets you looking at things a different way."

–WAYNE HYKAWAY, CARE PARTNER



"EPLED has given me the opportunity to encourage a more progressive lens that focuses on the person with dementia and their care partner. In one case, we were meeting with one of the research teams, and we were talking about dementia and the pandemic. Collectively, the EPLED members saw the primary issue differently than the researchers did. There was so much energy in our conversation that the researchers really heard what we were saying – and they revamped their research focus to align more with how we saw the issue. Honestly, that's something that I never thought would've happened. They really changed the trajectory and the focus, from system navigation to kind of a human rights focus."

–KAREN MYERS BARNETT, CARE PARTNER



"When I was preparing to be on a panel for caregiving and caregivers, I became unsure of myself. But after the panel discussion was over, there were such positive comments about what I had to say and what other people had to say. It made me feel, for the first time – and I've been advocating for a long time – that people were finally listening to me. I was very proud. The fact that I was given the opportunity to speak out, to say what I think, and that nobody stopped me, I was very grateful for having had a chance to do that."

–LINDA GROSSMAN, CARE PARTNER

**OCTOBER 2021**

Participation in planning and programming for the CCNA Partners Forum and Science Days.

**NOVEMBER 2021**

Involvement in developing and advising on two newly funded research grants.

Co-presenting at the Stigma and Social Inclusion Group Brainxchange Webinar.

**DECEMBER 2021**

Presentation to the Canadian Agency for Drugs and Technologies in Health (CADTH): "Patient engagement in research on dementia: a brief introduction."

Advising on content, design and messaging for the international Forward with Dementia website and resources.

**JANUARY 2022**

Panel participation in the CCNA's "Caring and caregiving for a person living with dementia" event.



“As a caregiver for my wife, who had early-onset Alzheimer’s, I was pretty well-centered on my situation, and how I was able to deal with the system. But I didn’t realize how cultural differences and racial differences could affect people in caregiving and in accessing support. In joining this group, I was made aware of that. And I’m hoping that that will be something we can continue to pursue with the researchers, to understand that it’s not all black and white. Every situation is different and the cultural and racial aspects of it are so important.” —DANIEL GAETANO, CARE PARTNER



“I like that we can choose the research opportunities. There’s no pressure. We can choose the topics that are relevant to us and where we think we can help. And the back-and-forth collaboration has made me feel like I’ve contributed, and that those contributions are valued. But what I really love about this group is that it always asks us this wonderful question: ‘What do you think?’”

—TONY LEAMON, CARE PARTNER



“I’ve been really taken aback by how great the people living with dementia in our group are with their advocacy, how they’re helping drive a lot of our conversations and our ideas. It’s so important that people living with dementia have a voice and they continue to steer things that are about them in the right direction. That’s been really important to me, especially because my dad [who died within three years of his early-onset Alzheimer’s diagnosis] did not have a chance to share his insight the way that a lot of the people in this group do. It’s just nice to hear that voice.”

—EMILY MCLELLAN, CARE PARTNER



“For me, one of the most rewarding experiences with EPLED so far was when we were able to add our commentary to the proposed legislation on aducanumab. Adding our voice, our opinions, to something so large and so international really meant a lot to me, because there’s so little done for any kind of dementia medication. There’s really nothing – it’s been years and years and it’s all still the same. So, to have something come out that’s so controversial and for us to be able to lend our voice to that, to be able to maybe nudge or push the national decision or opinion on it, that really meant a lot to me.”

—ROSETTE FERNANDEZ LOUGHLIN, CARE PARTNER



“I think working with some of the different researchers that I’ve worked with, it has created opportunities for me. When I was diagnosed [with vascular dementia], my career was taken away, and everything changed. When that happens, you question your own self-worth, you question everything you try to do – whether you’re good enough, whether you measure up, whether anybody will value anything you have to say anymore. My work with EPLED has given me confidence in myself again.” —CHRISTINE THELKER, PERSON LIVING WITH DEMENTIA



Learn more about the EPLED advisory group at [epled.ca](http://epled.ca).





The Association for  
Frontotemporal Degeneration  
**FIND HELP • SHARE HOPE**

AFTD's mission is to improve the quality of life of people affected by FTD and drive research to a cure.

We work every day to advance:

**Research.**

We promote and fund research toward diagnosis, treatment and a cure.

**Awareness.**

We stimulate greater public awareness and understanding.

**Support.**

We provide information and support to those directly impacted.

**Education.**

We promote and provide education for healthcare professionals.

**Advocacy.**

We advocate for research and appropriate, affordable services.

**[theaftd.org](http://theaftd.org)**



PHOTOGRAPHY: LAURA JOY PHOTOGRAPHY

# Shining a Light on Frontotemporal Dementia

This less-common brain disease affects personality and behaviour, and profoundly impacts lives.

**John McKenzie was just 49 years old when his wife, Kathy, noticed he was slurring his words on the telephone. She then started hearing it in everyday conversations, but John didn't think anything was wrong with him.**

"My husband owned his own automotive service centre, and someone actually called the Ministry of Labour to say that he'd been drinking on the job, because of the slurring," recalls Kathy. "Other people would ask me, 'What's going on? Has John had a stroke?'"

His garbled speech, combined with confusion, impaired judgement and poor decision-making – he had gotten lost driving home from Toronto one night (a familiar commute), and his business was close to bankruptcy – prompted Kathy to seek out medical intervention. Their family doctor in Barrie, Ont., brushed off her concerns, so Kathy began looking for a second opinion.

Following an extensive search for a new doctor, John was sent for an MRI and, within a week, the couple was consulting with a neurologist. The MRI scan showed that John's brain had damage to its frontal lobe.

After ruling out other possible causes, John received a diagnosis of frontotemporal dementia (FTD) in 2016, six years after the onset of symptoms. He has a secondary diagnosis of primary lateral sclerosis

(PLS), a low-spectrum ALS that can co-occur with FTD and impacts motor neurons. In John's case, his upper motor neurons that control the tongue are affected, accounting for his slurred speech. At the same time, his difficulty recalling words and putting together sentences are symptoms of cognitive impairment from frontotemporal dementia.

"It was a long journey to get help," says Kathy, who was relieved to finally have a diagnosis that explained John's unusual symptoms.

## What is frontotemporal dementia?

Frontotemporal dementia is a terminal disease that impacts the brain's frontal and temporal lobes. These lobes are associated with personality, behaviour, emotions, executive function, movement, and speech and language – and FTD causes a progressive and irreversible degeneration of brain cells in these areas.

The disease occurs when abnormal proteins aggregate in brain cells. In about 40 percent of FTD cases, these proteins clump together because of a family history of dementia, mental illness, or movement challenges, according to the Association for Frontotemporal Degeneration.



**“Frontotemporal dementia happens early enough that people are still working, and they may still be parenting young children. It’s really a crucial time in a person’s life.”**

*– Dr. Tiffany Chow*

#### **FRONTOTEMPORAL DEMENTIA (FTD) QUICK FACTS**

- FTD affects lobes associated with personality, behaviour, emotions, executive function, movement, and speech and language.
- About 10 percent of all dementias are FTD.
- FTD usually begins in middle age, between 45 and 64.
- FTD is often misdiagnosed as depression or even Parkinson’s disease.
- FTD also impacts family members who must adapt to changing relationship dynamics.

But for more than half of those diagnosed with FTD, there is no known cause as to why the abnormal proteins accumulate.

Researchers estimate that only about 10 percent of all dementias are FTD. By comparison, Alzheimer’s disease accounts for between 60 to 70 percent of all dementias.

“In frontotemporal dementia, one of the first identifying changes is personality and judgement, which may translate to going from very proper and polite to suddenly being very rude to others, for example,” says behavioural neurologist Dr. Tiffany Chow. “A lot of families really feel like they can’t recognize the person who has FTD because they are acting in a way that is so unknown or never before seen.”

In contrast, Alzheimer’s patients generally hold on to their personality, but not their memory. Memory loss is rarely seen in frontotemporal dementia, says Chow, who is based in La Jolla, California, and works in commercial research in the neuroscience of dementia at IQVIA, an organization that manages clinical trials for pharmaceutical companies, including those looking to develop symptomatic and disease-modifying therapies to treat dementia.

Another major difference between the two types of dementia is age of onset. While Alzheimer’s typically strikes in a person’s 70s, FTD usually begins in middle age, between 45 and 64, according to the Association for Frontotemporal Degeneration. In fact, it’s thought that frontotemporal dementia accounts for 20 percent of dementia cases in people under 65.

“Frontotemporal dementia happens early enough that people are still working,

and they may still be parenting young children,” says Chow. “It’s really a crucial time in a person’s life.”

Because it hits early and primarily impacts personality, it’s often misdiagnosed as depression or even Parkinson’s disease. As happened with John, it can take years to get a correct diagnosis.

#### **Symptoms of frontotemporal dementia**

In addition to changes in personality, mood, and social or financial judgement, people with FTD might also struggle with planning, organizing, staying focused or completing tasks. This set of mental skills is called executive function and helps us run a household or hold down a job.

John’s frontotemporal dementia was causing him to make poor financial decisions with his business, so Kathy made him retire after the diagnosis. His problem-solving skills were also deteriorating; for example, he could no longer figure out how to attach a Swiffer head to the mop handle.

Other symptoms of frontotemporal dementia can include language, speech and communication problems. Patients might have trouble finding the right word or maintaining a conversation. In addition to slurring his words, John began to struggle with reading comprehension and spelling.

Last, people with FTD can experience movement problems, such as balance issues, more frequent falls, difficulty walking, poor coordination, or tremors or shaking. As his FTD has progressed, John has experienced difficulty swallowing (he now requires a minced diet to prevent choking). He also developed weakness

Left: Dr. Tiffany Chow

Right: Kathy and John McKenzie



#### SYMPTOMS OF FTD



Changes in personality, mood, and social.



Poor financial judgement.



Difficulty planning, organizing, staying focused or completing tasks.



Deteriorating problem-solving skills.



Language, speech and communication problems.



Balance issues, frequent falls, difficulty walking, poor coordination, or tremors or shaking.

in his right hand and arm that impacts his fine-motor coordination and makes it difficult to open packages.

John is still functioning well enough to continue living at home with Kathy, who has assumed the role of caregiver.

“This is not what I envisioned for our retirement. I thought we would be travelling and having fun,” says Kathy. “It’s hard to even get a real hug [from John] anymore, but I understand it’s the FTD that’s doing it.”

#### A frontotemporal dementia diagnosis changes lives

Not only does FTD impact those who are experiencing symptoms, it also has repercussions for family members who must adapt to a new relationship dynamic with their loved one.

Naomi Mison found herself in this situation in 2007, when she was just 21.

Her mom, Frances Mison, was living in England at the time and experienced what Naomi describes as a “psychotic break” that would change the course of both of their lives.

After Frances was found wandering around a train station in her robe, she was placed in a mental health institution. Naomi and her brother brought their mom back to Edmonton to get her help – Frances had been living with bipolar disorder and depression for years, and they assumed her latest behaviours were stemming from mental health problems.

But this time, Frances’s symptoms – which included delusions and erratic sleeping patterns – were so severe that she was admitted to Alberta Hospital Edmonton. A PET scan showed brain atrophy and she was diagnosed with frontotemporal dementia at age 54.



Frances's diagnosis permanently changed her and her children's lives. Neither Naomi, then 21, nor her brother, who had a new baby, were in a position to care for their mom and manage her challenging behaviours, so she was placed into long-term care. Naomi worked with a lawyer to get guardianship and power of attorney so she could make decisions on her mother's behalf.

"In the blink of an eye I became the mother to my mother, and I don't feel that at that time in your life [early 20s] you're ready to assume that kind of responsibility," says Naomi. "For me it was life-altering."

Not only was she in the awkward position of making life-changing decisions for her mom, like placing her in a care home, Naomi also put her own future plans on hold. Instead of pursuing her dream to

travel the world, she stayed in Edmonton to help support Frances.

It was also a huge change for Frances, who went from living independently in a foreign country to spending her days in long-term care with people decades older. Due to risk of wandering, she was placed in the locked unit. Naomi says it was obvious her mom was unhappy and confused, but she couldn't articulate her feelings.

"In clinical practice when we make [an FTD] diagnosis, we try to warn families about what this diagnosis can mean," says Chow. "Part of it is to protect the finances, limiting access to funds, limiting access to the car. A person with Alzheimer's disease may have been deciding not to drive anyway. But these are younger people who want to drive around and be independent and they don't have that much awareness that they've changed."

“In the blink of an eye you become the mother to your mother, and I don’t feel that at that time in your life [early 20s] you’re ready to assume that kind of responsibility. For me it was life-altering.”

– Naomi Mison

#### LEARNING TO COPE

##### Becoming a Care Partner

Seek support from FTD organizations and from those with lived experience to help ease your transition to a new caregiving role.

##### Planning Ahead

Work with legal and medical experts to get organized to handle the impacts of the gradual loss of independence your loved one with FTD will face.

##### Finding Hope in Advocacy

Join with others to build awareness of FTD and the need for systemic change to find solace and keep you up-to-date with new disease-modifying therapies.

After John’s diagnosis, Kathy got power of attorney over her husband, with John’s consent, and she also went to the bank to secure their finances. Her relationship with John changed from wife to caregiver, which they both found frustrating. But the biggest blow came when the neurologist decided it was time for John to give up his driver’s license in 2018.

“That was the absolute worst for him,” recalls Kathy, who says John knew he had dementia, but was in denial. “It was a big scene in the parking lot of the hospital.”

The gradual loss of his independence has resulted in what Kathy calls “temper tantrums.” Reacting this way is not unusual, says Chow.

“It’s hard for people with FTD to accept that they’ve changed enough that they are losing privileges,” Chow explains. “You have lost the privilege to work, you have lost the privilege to eat what you want, you have lost the privilege to spend all that you want, you cannot drive a car.”

#### Living with frontotemporal dementia

There’s currently no cure for or treatment to stop the progression of frontotemporal dementia, but medication and therapy to manage symptoms can help. And there are support groups and resources available for caregivers.

Kathy joined both an ALS support group and an Alzheimer’s support group and says she always learns something new or relatable during the virtual sessions. In fact, the Alzheimer’s Society suggested music therapy for John because he’s a self-described “metalhead” who likes

playing bass guitar. He listens to music and plays guitar during each session with Music Therapy Services of Simcoe County and is even learning how to read sheet music. The goal of the sessions is to keep John engaged in something he enjoys. An added benefit is that music therapy boosts his mood.

“He loves it,” says Kathy. “When he comes home, he’s downstairs practicing what he’s learned. He’s using his brain and he’s in a happier mood, which lasts a couple of days.”

John also takes amitriptyline, which helps ease teeth grinding and drooling. For the time being, Kathy is able to manage his temper tantrums and lack of empathy without a prescription, but some patients with FTD do take medications to temper aggression, relieve symptoms of OCD or anxiety, or boost a depressed mood.

Doctors must take a very individualized approach to treating each patient, explains Chow. Ideally the practitioner will work with a multidisciplinary team to evaluate a patient’s symptoms and come up with a management plan. Frances’ doctors, for instance, have her taking galantamine, a drug commonly used to combat the cognitive decline associated with dementia.

#### From caregiver to advocate

After a decade caring for her mom, both in Edmonton and more recently long-distance from Kelowna, Naomi realized the best medicine for her, personally, was to share their story. She started a blog called Discuss Dementia in the hope of reaching other young caregivers like herself. She has been bolstered by people who have

“Things don’t change without building awareness, so that’s part of why I’ve been more vocal in the last five years. I’ve found a lot of solace in advocacy, and finding other people ignited by the fire of wanting change.” – Naomi Mison



thanked her for sharing her journey, and who feel camaraderie knowing they are not alone.

Naomi also felt like there weren’t (and still aren’t) a lot of supports in place for dementia when it affects people younger than 65. No one handed her a binder filled with dementia hacks and resources to help her mom, so she’d like to fill that gap.

In addition to her blog, Naomi is a member of the Leadership Group of Caregivers with the Alzheimer’s Society of BC. She has also participated as a panel speaker during both Alzheimer’s Awareness Month in Canada (January) and World Alzheimer’s Month (September). These efforts have helped raise awareness about the disease and its impact.

“Things don’t change without building awareness, so that’s part of why I’ve been more vocal in the last five years,” says Naomi. “I’ve found a lot of solace in advocacy, and finding other people ignited by the fire of wanting change.”

Naomi ultimately wants systemic changes to happen. She’d like to write a private members’ bill for caregivers of people living with dementia.

“I would legislate increased support for at-home and respite care,” says Naomi,

who felt pressured into placing her mom in long-term care because there wasn’t any community support to keep Frances at home.


### What the future holds for frontotemporal dementia

Another person working to spark change is Tiffany Chow. As a medical strategist for IQVIA, she counsels pharmaceutical companies on what it’s like to live with FTD. This way, clinical trials will be designed with those considerations in mind, specifically the behavioural changes and early-onset criteria that would inform recruiting and retaining suitable trial candidates.

Chow points out there are a number of FTD-related clinical trials currently underway (not connected to IQVIA), including trials for disease-modifying therapies to address abnormal tau (protein “tangles” associated with dementia). Other trials address those patients with C9orf72, or progranulin genetic mutations, which are known to cause FTD, and some are using gene therapies to “switch off” unwanted production, or to fill in for missing protein production, that can cause degeneration.

“There’s hope that these trials will reveal something that does work,” Chow says. “It’s been frustrating for families living with FTD that the solutions have eluded us for as long as they have.”

What’s more, funding organizations like the National Institute on Aging are paying more attention to FTD because frontotemporal dementia is a good candidate for emerging cell and gene therapies. Since researchers have identified specific genetic mutations linked to FTD, it’s “incentivized the pharmaceutical industry to invest in developing disease-modifying therapies,” explains Chow, because success in treating frontotemporal dementia might finally be within reach.

“That’s giving me a lot of hope,” she says. 



#### FTD RESOURCES

For a frontotemporal dementia overview, and information on clinical trials, research, and genetic testing, The Association for Frontotemporal Degeneration is a great place to start.

[theaftd.org](http://theaftd.org)

DementiAbility provides dementia education, resources and tips on approaches to dementia care.

[dementiability.com](http://dementiability.com)

A one-stop shop for frontotemporal dementia research, The Bluefield Project also runs cutting-edge FTD clinical trials.

[bluefieldproject.org](http://bluefieldproject.org)

The Alzheimer’s Society of Canada offers support for, and education about, all kinds of dementia (not just Alzheimer’s), including frontotemporal dementia.

[alzheimer.ca](http://alzheimer.ca)



I am so glad I found this amazing organisation.

Diana, USA

DAI saved my life.

Bonnie, USA

Everyone is really supportive.

Bill, Australia

They were life saving for me.

Christine, Canada

I felt so welcome like a warm hug.

Emily, Singapore

It saved my sanity, I'm so thankful I found DAI.

Mithrani, Australia

DAI gives me hope every day.

Natalie, Australia

You never feel alone that's what you'll find at DAI.

Terrie, USA

I found out I wasn't alone and I didn't need to be ashamed.

Wally, USA

## Is DAI the antidote for dementia?

We all know there is still no cure for dementia, and that research for a cure remains elusive. However, that is no reason for people to be treated as if they are at end stage of dementia straight after a diagnosis.

Dementia Alliance International is an international group which launched on 1 January 2014, whose membership comprises solely of people with a diagnosis of any type of dementia now from 49 countries. They are people of all ages, cultures, and demographic. Whether living alone, living with a partner, or living in a nursing home; everyone is welcome.

This innovative group offers online peer to peer support groups and cafes with other members where people are

free to meet, laugh, talk and cry with people living with a diagnosis. The value of peer-to-peer support cannot be underestimated, and members of DAI consistently report it has been 'life-saving'.

So, if you have been diagnosed with dementia or know someone who has, it may be just the antidote needed to start living with dementia.



The global voice of dementia



email: [info@infodai.org](mailto:info@infodai.org)



website: [www.infodai.org](http://www.infodai.org)



[www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)



[@DementiaAllianc](https://twitter.com/DementiaAllianc)

# The County Day Program

A new approach to long-term care.



Danielle Preston



Laura Elliot

**Long-term care homes are full of life experiences.** Each resident is a unique individual with a rich personal history that does not disappear with age, including for those living with dementia.

This reality is what fuels one care home in Prince Edward County, Ont., to actively reject the common belief that all long-term care homes are depressing and lonely, and to instead focus on providing meaningful, person-centred care for its residents.

Like many care homes, H.J. McFarland Memorial works with limited resources. But its motivated staff has proven that through hard work, compassion and a little creativity, homes like these can become havens.

## Accepting change

Danielle Preston oversees recreation and volunteer services at H.J. McFarland Memorial. She and its executive director, Kyle Cotton, were brainstorming about how to better manage and improve repeated behaviours of some residents when the idea of creating an innovative day program was born. Together, they envisioned a place, on-site, where residents would feel safe, warm and joyful while keeping busy doing activities they loved.

“It’s not something that’s been used in long-term care that we were aware of,” says Preston. “A day program in the community is usually for people still living at home.”

Preston reached out to Laura Elliot, a representative from DementiAbility, which is a global organization that focuses on person-centred care by recognizing the connections between a person’s brain, life story, environment and behaviour and working to uncover their abilities.

A gerontologist and educator, Elliot has been the program coordinator for the DementiAbility team for six years, helping to provide education, resources and new approaches to dementia care. With a great deal of experience in finding innovative ways to improve care by listening to people impacted by dementia, she was immediately supportive of Preston’s idea to create a day program at H.J. McFarland Memorial.

“One of the things families find difficult when their loved one goes into long-term care is that they will miss their day program because they loved going,” Elliot says.

With Elliot’s guidance, based on DementiAbility methods, Preston, Cotton and other members of the care home staff spent the next two months building out the program.



## Shaping a vision

Of course, planning for a new day program with limited resources requires hard work and creativity, so the team took it step by step.

“It started with the care home staff coming to the [DementiaAbility] workshop, getting inspired, going back and saying, ‘How can we do this here?’” says Elliot. “We had all the research and all the things we knew had worked with other DementiaAbility organizations. But also, we had the knowledge that [Preston] had from working day to day with the people in her care.”

Following the DementiaAbility workshop, six participants (residents) were picked to take part in the care home’s program. Selection was based on Elliot and Cotton looking at factors such as behaviours, falls, pain, continence, meals, medications and personal history, and deciding, from there, who might benefit most from the initiative.

Then, program activities were shaped based on each participant’s identity, past roles and hobbies.

“If we had someone that worked at a grocery store, for example, we would give them coupons that they could sort and clip,” says Preston.

An underused family dining room was chosen as the program’s site. “We converted the space, changing the artwork, decor and flow of the room. We purchased cube shelves and created 60 to 80 kits filled with activities such as card sorting, cutlery sorting, jewellery making, glasses cleaning and Tupperware matching,” she says.

Supplies, storage items and decorations were bought by redirecting funds from the operating budget, a move that was justified by the potential impact the program would have on the home overall.

It was also determined that a member of the home’s activity staff would be tasked with running the program each day. Plus, one of the floor support workers would visit to provide personal care if needed, and a registered practical nurse would come to give medication.

And for program evaluation, Preston created a personalized plan for each participant and shared it with staff to monitor changes in behaviour and improvement.

After this careful planning, the program welcomed participants on July 4, 2021, operating seven days a week from 8:30 a.m. to 3:00 p.m., with a one-hour break after lunch. It ran through to December 2021 before COVID-19 restrictions halted activities.

A selection of DementiaAbility-inspired activities.



**COUNTY DAY PROGRAM OUTCOMES**

.....  
**Person-centered care decreased falls and expression of high-intensity needs.**  
 .....

**Meaningful engagement improved food and fluid intake.**  
 .....

**Resident boredom and loneliness were eased by purposeful activity.**  
 .....

**Staff morale and overall operational efficiency were increased.**  
 .....

**Seeing results**

Despite its short operation time, Preston says the day program showed impressive results. “There was a reduction in falls and responsive behaviours, and improvements in food and fluid intake,” she says.

She attributes a large part of this success to the person-centred approach. For example, before the program, one participant would not sleep anywhere – including in his own bed or chair. Within the first week of the program’s launch, staff found him sleeping on a couch in the room that hosts day-program activities.

“He’s settled here because we were able to take that dedicated time to allow him to feel that this is his home,” Preston says.

Though participants spent all their time together, the person-centred activities tailored to each personality were a hit. Providing a former carpenter with different building materials to put together, for instance, made him feel like he had a goal and purpose each day.

Preston notes that staff morale also improved as they saw results.

“When we started, there was a bit of hesitancy in giving all this one-on-one time. But within two weeks, the staff was like, ‘This is actually working.’ Then it became, ‘How can we as a team make it better for the resident?’” she says.

Both Preston and Elliot also noticed that, as a whole, the care home started running more efficiently.

“Staff had time to dedicate to the other people who weren’t having those high-intensity needs and were getting more time allocated to them,” Elliot says.

Preston, who has worked in long-term care for about a decade, says she has finally found a care model she knows will help to improve long-term care moving forward. By taking that extra time to investigate individual residents’ histories and needs, as DementiaAbility recommends, Preston and the staff found ways to personalize care and ease boredom and loneliness, while giving purpose to each day.

“I’ve finally been able to be a part of helping people see change,” she says. “Our goal now is to bring DementiaAbility with us and make it our care model so that every home area, every staff member and every interaction we have is focused on DementiaAbility methods.”


With the day program’s return slated for Spring 2022, Preston can again look forward to what the future holds for its participants living with dementia.

**Calling for action**

H.J. McFarland Memorial’s triumph in creating a day program shows how long-term care can be changed despite limited resources, through teamwork, dedication, innovation and person-centred care. Preston and Elliot hope their story encourages other care homes to take initiative and help change the face of long-term care.

“Not everyone is going to have the resources to establish a dedicated space, but you can implement the ideas and the principles,” says Preston. “Think about how each of your residents is a person and focus on what they need. Take the risk and take that step.”

In her role as a DementiaAbility educator, Elliot is already helping others make these changes.

“This field needs more education. Then we can translate knowledge to practice,” she says. “My goal is to create a world where people with dementia want to live, where staff want to work and where families want to visit – this is what the future of long-term care will be.” 

By Jennifer Prescott and Shannon Cleary

# The Fear of Dementia

—  
**Breaking free from stigma.**

**“Oh, dear God, I hope I never get diagnosed with this.”**

That was a common statement among Christine Thelker and her peers when they'd chat over lunch. Thelker was a nursing assistant in Vernon, BC, at the time and had spent much of her career in dementia care. While she was passionate about improving the lives of people living with dementia, she, like many of her co-workers, was terrified at the notion that she would someday experience the same symptoms as those she cared for.

Eventually, her worry became reality. In 2015, she was diagnosed with vascular dementia at just 56 years old. She says she was shocked and numbed by the fear of what was to come. Her career ended abruptly, and her loved ones began worrying about how she would navigate daily life.

“Things just started happening around me, and I stood there, unable to think far enough ahead to know the right things to do,” says Thelker. “I was just listening to people who thought they were caring for me and making good decisions for me, but those [decisions] were all based on stigmatized ideas of what dementia looks like.”

Loved ones advised Thelker to sell her house, expecting that soon she'd be unable to function in daily life. This, in turn, led her to stress over when she'd need to move to a care home, and which one she should choose.

For the first two years following her diagnosis, the stress caused by the fear of her future led Thelker to isolate herself from others in order to avoid judgment and difficult conversations.

But now, seven years later, it's clear to Thelker that the concerns she had about dementia rapidly rendering her incapable were unfounded. Though she needed an adjustment period to adapt to her new reality, today, Thelker still lives alone, with a volunteer coming to her home once a week to help her with technology. She also belongs to several dementia-related committees and advocacy groups, and she's an accomplished writer whose abstracts were presented in a conference in London in the spring of 2022.

Looking back, Thelker says her early fears, and those of her loved ones, were fuelled by stigma and misconceptions about what the dementia journey looks like, and by thinking only about the late stages of the disease.



Christine Thelker

**“I was just listening to people who thought they were caring for me and making good decisions for me, but those decisions were all based on stigmatized ideas of what dementia looks like.”**

*– Christine Thelker*

### **What do we fear?**

Dr. Francesca Farina, a neuroscientist in Dublin, Ireland, and a Senior Atlantic Fellow for Equity in Brain Health for the Global Brain Health Institute (GBHI), confirms people tend to fast-forward immediately to the end-of-life stage when thinking about dementia.

“People still have the perception that you get a diagnosis of dementia and then [your life is over],” she says.

Farina, who dedicates much of her work to understanding the individual and societal impacts of fearing dementia, aimed to dig deeper into the relationship between fear, memory and quality of life in her 2020 study titled “Fear of memory loss predicts increased memory failures and lower quality of life in older adults: preliminary findings from a fear-avoidance of memory loss (FAM) scale.”

Using a sample of older adults from the Dublin community, Farina was able to find the common reasons people fear dementia. They include loss of identity and personhood, becoming dependent on others, being treated differently by friends and colleagues, embarrassing oneself and causing embarrassment for loved ones.

Farina says these fears are caused by negative perceptions of dementia that stem from old, stigmatized ideas and treatment methods. For instance, in the past, the media has shown people with dementia confined to institutionalized environments or in vegetative states.

“I think some people are still very confused about what dementia is,” Farina says. “When you have that confusion, that can spur fear – a fear of the unknown.”

### **The impacts of stigma and fear**

According to Farina, stigma and fear go hand-in-hand, which leads to discrimination for those already living with dementia. This can occur in the form of basic human rights being denied to them.

“[Due to fearful loved ones], people may no longer have control over their own affairs, even when they feel that they still have a lot of capacity,” Farina says. “Those rights are taken away from them.”

Thelker’s experience serves as an example of this form of discrimination. Not only did her diagnosis end her career, but her loved ones immediately began to take control of certain affairs based on what they’d seen and heard about dementia. They couldn’t imagine that, post-diagnosis, she’d be capable of accomplishing all that she has in the last seven years, or that she’d still be living alone with minimal assistance.

Because society views dementia in a stigmatized way, Thelker’s voice was quieted in planning for her own future.

Ursula Ryan, a retired teacher in rural Nova Scotia, feared her husband, Dan, would experience the same sort of discrimination after he was diagnosed with dementia at age 66.

“I didn’t want to be isolated, and I didn’t want him to be,” Ursula says. “I didn’t want this stigma.”

As time passed, she indeed watched stigma and fear chase people away. “Friends that I’ve had in the past don’t come around anymore and haven’t been around



Dr. Francesca Farina

**“If we don’t see people with dementia living their lives in neighbourhoods with supports that make sense, and help them to maintain their dignity, then we’re never going to reduce the fear.”**

*– Dr. Francesca Farina*

for three years,” she says. “That was a big shock to me. You know it’s just because they can’t accept it.”

Still, Ursula finds hope and comfort in the fact that not everybody has stayed away. For example, as she continued to bring Dan to church with her, other congregants were welcoming and accepting of his presence, even when he would become confused or slightly disruptive. “They are all comfortable enough that I’m not hiding him in a closet,” she says.

Farina’s study revealed that, not only does fear cause discrimination for persons living with dementia (as Thelker and Dan Ryan’s stories show), it can also become a factor for decreased health in people who live without dementia.

In fact, the participants who feared dementia the most reported more memory problems and were linked to reduced overall well-being, despite having performed averagely on an objective memory test.

These findings suggest that fearing dementia can cause excessive self-monitoring of potential symptoms, leading to distress and fatigue, which can then increase real cognitive failures.

For example, when we worry about forgetting a name and then fixate on what

forgetting a name may represent, we may increase the likelihood of forgetting that name, thus strengthening our fear of cognitive decline.

Farina says this self-fulfilling cycle can lead to unnecessary and unproductive behaviour, such as avoiding social engagements or steering clear of activities requiring cognitive effort, like card games and other once-loved hobbies. Avoidance may provide short-term relief, she says, but the long-term impact can be quite harmful.

“Your world becomes smaller and smaller because you’re trying to keep yourself safe,” Farina says. “You’re not getting cognitive stimulation, you’re not making those social connections with people, you’re not challenging yourself to break that cycle.”

And yet, Farina points out that a certain level of fear of dementia is not something to be dismissed entirely. After all, it can motivate people to seek assistance and understanding, to adopt healthy lifestyle behaviours and to support and empathize with others.

“The fear we’re [concerned] about is a higher level of fear – fear that is really persistent, intense and starts to interfere with our day-to-day well-being,” she says.

### **Shattering stigma to end fear**

Addressing the stigma associated with dementia will help to break down this fear and build more responsive, compassionate communities that better support everyone.

Farina suggests some strategies for challenging the societal stigma, rather than sticking to the old ways of looking at dementia. These include increasing public education around what dementia really is, how common it is, its symptoms, and what people can do to keep their brains healthy and active.

Farina also says it would help if people living with dementia were seen more often outside of institutionalized settings.



“If we don’t see people with dementia living their lives in neighbourhoods with supports that make sense, and help them to maintain their dignity, then we’re never going to reduce the fear,” Farina says.

Ursula Ryan agrees with this notion and is doing her best to speak out about ending stigma in her community. In fact, when Dan’s favourite bench was removed by city workers, Ursula fought to have it replaced. She explained to civic leaders that, over the last couple of years, the bench had served as a social hub for Dan – people passing by would often stop to talk to him as he sat there.


Fostering conversation about Dan’s lived experience led to the bench’s return, and notably, to greater understanding. Ursula says if there were more social engagement activities for people living with dementia and their care partners, perhaps others would judge less and be more comfortable around them.

As Dan enters his ninth year of living with dementia, Ursula continues to work toward building awareness around the disease and decreasing society’s fear while trying to keep him at home as long as she can.

Thelker, meanwhile, continues to share her lived experiences of dementia with the aim of offering hope to people who worry they will one day receive their own diagnosis.

“As time goes on, you start to redefine yourself,” says Thelker. “In many ways, I have a deeper, richer life than I did before, and it no longer matters to me how long the journey is.”

She acknowledges that the path may be hard, but perhaps her story of adapting can help to break down the stigma and dampen the fear of living with dementia.

“I found my laughter again, I found my joy again,” she says. “I found out that, although I’d been handed this diagnosis, I could still live, and I could still be happy.” 

**“In many ways, I have a deeper, richer life than I did before, and it no longer matters to me how long the journey is.”**

*– Christine Thelker*



## Patrick Ettenes

**Navigating your thirties with early-onset dementia.**

**A dementia diagnosis can be hard to accept at any age.**

But imagine being told you have dementia in your early thirties. Suddenly, typical thirty-something affairs such as clubbing with friends, travelling, dating and career advancement become more complex as uncertainty muddies the future.

So goes the story of Patrick Ettenes, a 38-year-old man living in Manchester, England. In 2015, Ettenes suffered a nervous breakdown and a stroke. A subsequent brain scan exposed extensive deterioration. At just 32, Ettenes received a diagnosis of frontal lobe atrophy, a type of dementia caused by progressive nerve

cell loss in the brain that can affect behaviour, personality, language and movement.

He couldn't see it at the time, but the following years would uncover his resiliency.

The stroke had left him unable to walk, talk and write, so first he slowly built his body back to health. Then he sought ways to live well in his ever-changing world. For a while he attended dementia support groups, but found they consisted mostly of married people over 50 who were cared for by their children. As a young single gay man, he struggled to fit in.

Having lived with HIV for more than a decade while battling through drug addiction, an eating disorder and an abusive relationship, he came to realize he was adept at overcoming life's challenges.

In 2018, Ettenes created the LGBT Dementia Network, an advocacy group dedicated to LGBTQ2+ community members living with dementia. And in 2019, he co-founded Bring Dementia Out with the Alzheimer's Society, a program to train and assist housing and dementia organizations in addressing the community's unique experiences.

Today, Ettenes is an award-winning activist, public speaker and writer who plans to stay busy advocating. He wants to show others that life doesn't end with a dementia diagnosis – and that dreams can still be realized.


Here, Ettenes shares some of his struggles with dementia and reveals how he strives to make the best of every day:

**“Living with dementia doesn't just mean you have a condition taking away your memories. If you're younger, I think it takes away your voice and develops a lot of insecurities. I still want to achieve, but every year my condition takes a bit more out of me.**

**I have fantasies in my head of things I want to achieve, so that keeps me going. I have a fantasy to go on the beach when I'm by myself for the first time and watch the sunset. I try to embrace being on my own and not see it as a weakness, but as a strength.**

**The journey I have to go through is not going to be easy, but if I can continue getting a bit of support from the world and from the people around me who allow me to be me, then I can bring a lot more to everyone's life.**

**My advice for others living with dementia is to accept that each year things will change. Get the right people around you to cry with. It's okay to get upset. If you want to scream and shout, do it.**

**My motto is to try to keep as much of me as possible. I've always been different and unique; I like to be a little bit crazy. I don't want to lose that part of me.”** 

**RDS** Rare  
Dementia  
Support

**C A N A D A**

Advice • Community • Learning

**RDS Canada is a support service for Canadians living with or supporting someone with a rare or young onset dementia.**

RDS Canada provides:

- Tailored information and learning resources,
- Individual, family and group support,
- Connection with others who are affected by similar conditions,
- Services delivered virtually across Canada by our team of practitioner specialists, researchers, educators and individuals with lived experience.

**Contact us at:**

[RDSCanada@nipissingu.ca](mailto:RDSCanada@nipissingu.ca)

  @RDSCanada



Funded through a generous donation from The Hilary and Galen Weston Foundation. Supports provided in partnership with RDS UK, a world-leading service provided by University College London Dementia Research Centre and funded by The National Brain Appeal.

# End the stigma

All party dementia caucus **Personalized Care**

**Human rights**

Better post-diagnostic support

Increased dementia-specific skills and knowledge

**Dementia inclusive communities**

Family care partner tax refunds or allowance

**Single point of contact to navigate the system**

Family as essential part of a care team



Dementia  
Advocacy  
Canada

*Voices of Lived Experience*

**Help us shape an inclusive Canada.**

We are a grassroots group of Canadians living with dementia and care partners. Our mandate is to establish an active and respected role in decisions about government policies and programs that impact our lives.

Join us and share your story at [DementiaCanada.com](https://DementiaCanada.com)